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LISTENING TO THE GROUPS

Rotary Club of Hamilton Self Help Centre

COMMUNITY RESEARCH
AND DEVELOPMENT PROJECT



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LISTENING TO THE GROUPS Rotary Club of Hamilton Self Help Centre COMMUNITY RESEARCH AND DEVELOPMENT PROJECT

AUGUST 1996

Prepared for the Rotary Club of Hamilton Self Help Centre Board of Directors

by

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in collaboration with

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Supported by Human Resources Development Canada

Based on data collected by Ronaldo Parada and Caroline Neufeld, and entered into a NUD.IST database by Caroline Eyk, Ronaldo Parada and Caroline Neufeld.

The views expressed herein are those of the author and do not necessarily reflect SPRC policy.

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1.0 INTRODUCTION

1.1 Background

The Self-Help Network of Hamilton-Wentworth was formed in 1989. The purpose of the Network is, "to encourage the self-help movement in Hamilton by offering groups a chance to share knowledge and resources." ¹ Its mission is, "to provide support, resources and to foster the growth and development of self-help support groups." ²

The Rotary Club of Hamilton Self-Help Centre, herein referred to as the "Self Help Centre" opened its doors in the spring of 1993, in the newly renovated West Avenue School, a heritage building owned by the City of Hamilton. Its purpose: "to provide a networking facility for members of the Self Help Network. Here groups can meet, share information and hold special events." The Centre began as project of the Social Planning and Research Council of Hamilton-Wentworth (SPRC) — the building's main tenant — with the intention that the Self Help Network Board of Directors would eventually take over and operate the Centre independently; a target date of 1998 was set. Until then the SPRC would act as onsite landlord, oversee building operations, supervise special projects and assist with Board development and development of policies and procedures.

By November 1994, completed renovations allowed the Centre to offer six meeting rooms ranging in capacity from 10 to 120 persons. A variety of projects, meetings, workshops and other events took place in the first two-and-a-half years of the Centre's life. In the summer of 1995 the Self Help Network Board of Directors agreed on a set of goals and objectives to guide its work over the next two to three years. [See Appendix A]

¹ Source: The Self Help Network of Hamilton-Wentworth brochure, November 1995.

²lbid..

³ Ibid.

1.2 Rationale

Self help/mutual aid groups vary widely in size and character and cover a growing assortment of issues -for example: addictions, bereavement, employment, mental health, physical conditions, family situations
and gender issues. New groups are always forming, resulting in groups at different stages of development
at any given time. Due to the wide range of issues that self help groups deal with and the different stages
that the groups are at -- recently formed, expanding, disbanding, transitioning, etc. -- what may be
important for one group may be less so for another one.

Although it had clarified its goals and was offering meeting room and basic communications services at the Centre, the Board lacked consistent information on which to base policy development and decision-making. An earlier grant from the Ontario Ministry of Health - Health Promotions Branch had allowed the production of a group facilitation training manual, Towards Effective Self-Help, as a project of The Prevention Network of which the Self Help Network was a member. This manual has since been available for sale to groups and interested others, but the sporadic nature of staffing at the Centre has made it difficult to offer personal assistance to groups or individuals — or, indeed, even to find out what assistance such persons might need.

In the fall of 1995, support was obtained from Human Resources Development Canada to hire two project staff to conduct a combined survey and outreach project among self help and other support groups in the Hamilton area.

1.3 Project Objectives

- To develop and implement outreach activities with self-help groups in the Region of
 Hamilton Wentworth, using the Community Information Services Directory of Self Help/Support
 Groups (April 1995), Self Help Network membership list, and other relevant sources;
- To collect data from self help groups about their group resources, their membership, type of group, accessibility, satisfaction with their group and the Rotary Club of Hamilton Self Help Centre, as well as what services the Rotary Club of Hamilton Self Help Centre should be providing to them;
- To document any unintended "spin-offs" of this community research and development project;

⁴Carol Town, for The Prevention Network of Hamilton-Wentworth (1993)

To inform the Self Help Centre Board of Directors about the results of this community
research and development project, and make recommendations regarding Centre operational
issues, policies and strategic planning;

To distribute findings and recommendations to the self-help community which participated in this
project, and to other interested groups and organizations in the region of Hamilton-Wentworth.

2.0 METHODOLOGY

2.1 Approach to Groups

The project team wanted to get an overall picture of the state of self help in our community, but didn't know how many groups there might be, where we might find them, or what approach would be best. We had been considering a two-stage approach -- an initial outreach interview followed by a telephone call or second visit for data collection purposes, but changed our minds after a consultation with Lori Dessau, Executive Director of Self Help Canada, former Executive Director of the Toronto Self Help Clearinghouse (now the Self Help Resource Centre of Greater Toronto) and current member of the Self Help Centre of Hamilton-Wentworth Board of Directors. Lori reminded us that self-helpers — while they would probably be happy to make time for us once -- are busy people with priorities of their own, who would rather we take care of our agenda all at once and then let them get on with their work. She encouraged us to keep it very conversational, letting the self-helpers tell us their stories and keeping our direct questions to the minimum we needed for data collection. These views were echoed by Randi Fine, Executive Director of the Self Help Resource Centre of Greater Toronto, and Allan Strong, Coordinator of the Ontario Self Help Network.

Based on this sage advice, we decided a personal interview was the best way to accomplish both our outreach and data collection objectives. We developed an interview package, consisting of a six-page questionnaire and a set of promotional materials, which formed the basis for each meeting. [See Appendix B] Although the questionnaire was structured, we tried to let each meeting find its own conversational rhythm, and filled in the data as the information came up in the conversation.

Generally, the interviewee was the `contact person' -- that is, a group member who knew the group well, had been involved in the group's activities for some time, and was the group's designated contact for anyone making inquiries about the group. When the group permitted, we attended a self-help group meeting and participated or observed the group dynamics. In the case of professionally-led and some self-help/mutual aid groups, the interviewee was the group facilitator or support person, not a group member. Some of these were involved with more than one group, in which case we tried to complete a separate questionnaire for each group. When it was not possible to meet in person, the interviews took place over the phone. This was also the case with Self-Help Network members: because they were already familiar with the Rotary Club of Hamilton Self Help Centre, we could accomplish our objectives in a telephone interview, using the same questionnaire.

Most of the interviews were conducted by the Community Development Worker — approximately 80 - 85% - and the rest were done by the Community Researcher. This was a way both to ensure consistent data collection and to appreciate the realities of the interview situation.

2.2 Identifying the Self Help Groups -- Who is and Who isn't?

There is considerable discussion in the self help community and the literature about what self help really is, and what distinguishes it from other supportive or personal growth experiences. In popular culture, the term is applied fairly loosely to a potpourri of activities including self-taught educational packages, entrepreneurial enterprises, and any group experience where members, by joining, have helped themselves. Each of these has its valuable place in society, but a self help centre needs to be more precise in its understanding in order to be clear about both the services it is offering and the groups to which it might refer individuals.

Francine Lavoie and Miriam Stewart (1995) assert that, "... a mutual-aid (i.e. self-help) group can be seen as a community resource... [while] ... a support group is a form of professional service...." and go on to discuss the difficulties of arriving at clear definitions: "Even when these definitions are well articulated and understood, anyone who ventures into the field to try to compile an inventory of available groups in a given community faces a formidable challenge. Each group has its own history and particular context, resulting in a combination of diverse components into a coherent and unique whole."

Orford has written, "It is difficult to formulate a definition of self-help which does justice to this rich diversity of organizations." One which is widely quoted and which is broad enough to do justice to most cases, is that of Katz and Bender (1976):

"Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasise face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently 'cause'- oriented, and promulgate any ideology or values through which members may attain an enhanced sense of personal identity."

In addition to the various common life experiences that bring people together, self-help groups also vary considerably in the purposes they serve. This is shown in a recent review of literature which offers the following list of purposes: social support; information sharing and education; identity formation; affiliation

⁵ "Mutual-Aid Groups and Support Groups: The Canadian Context," Introduction to Special Issue on Mutual-Aid Groups and Support Groups, <u>Canadian Journal of Community Mental Health</u>, (14)2, Fall 1995, p6.

⁶Orford, Jim: <u>Community Psychology -- Theory and Practice</u>. John Wiley and Sons, Chichester, 1992, p224, citing Katz, A.H. and E.I. Bender: "The Strength in Us: Self Help Groups in the Modern World" New Viewpoints, Franklin Watts, New York, 1976

and community; personal growth and transformation; advocacy and collective empowerment. In the midst of this variety, mutuality of helping and common life experience are two central characteristics which distinguish self help groups from, on the one hand, self-managed individual activity, and on the other, support groups led by a professional, paid worker who does not share the common life experience that brought the group members together. To make this clearer and avoid the ambiguity created by the term, "self-help," many are now using the combined term "self help/mutual aid," or "mutual aid" or "mutual help" by themselves. This report generally uses the term "mutual aid" and, occasionally, "self help/mutual aid."

Self-taught learning packages (and other self-managed programs) and professionally-led support groups, then, are not true examples of self-help/mutual aid.

Parallel but not unrelated to the community research and development project, similar discussions were occurring among Board members of the Self Help Centre. In May 1995, the Board adopted a list of eight "Characteristics of Self-Help Groups..." which support and amplify the central importance of mutuality, common experience, and groups run by the members themselves. [See Appendix C] The first three characteristics bear this out:

- 1. Self help or mutual aid is a process wherein people who share common experiences, situations or problems can offer each other a unique perspective that is not available from those who have not shared these experiences.
- 2. Self help groups are run by and for group members. Professional providers may participate in the self help process at the request and sanction of the group and remain in an ancillary, or consultant role.
- 3. Activities focus on mutual support through discussion and sharing of information and experiences, but may extend to other activities and ways of interacting.

Such discussion had direct methodological implications for the project team because our primary source for identifying groups we wanted to visit, the Self Help/Support Groups directory published by Community Information Service, contained both mutual aid groups and some professionally-led support groups. We could not always tell from the description, however, which was which. In addition, we knew that groups varied widely in their access to resources, amount of institutional support, and how involved they were with the professional community in their area of interest — information that had implications for which services groups might be seeking from the Self Help Centre. Because we wanted both to learn as much as possible about self help in Hamilton-Wentworth and to end up with information precise enough to permit us to clearly distinguish one kind of group from another, we decided to contact and interview, if possible, every

⁷ Hyndman, Brian: "Does Self-Help Help? A Review of the Literature on the Effectiveness of Self Help Programs". For the Ontano Self Help Network, a Sponsored Project of the Self Help Resource Centre of Greater Toronto Draft for Discussion Centre for Health Promotion, University of Toronto March 1996.

group listed in our two main sources, excluding none. We also asked for referrals to unlisted groups, again without exclusion, and sought to interview them as well. In each interview, we asked questions about leadership, agenda-setting and mutuality in order to approximately categorize that group according to working definitions. [Please see Section 2.5 below]

In summary, the self-help groups, support groups and programs interviewed and included in this report were identified from the following sources:

- Self-Help/Support Groups of Hamilton-Wentworth, published by Community Information Service,
 Hamilton-Wentworth, April 1995;
- Self Help Network list of members and former members;
- Other groups identified by referral or in the course of other activities.

2.3 Outreach

In the absence of regular staffing, it had been impossible for the Self Help Centre to establish or maintain consistent contact with its constituency, the self help groups. One very important goal of the project was to establish or reestablish contact, let the groups know what the Centre had to offer, and express our desire to be of service. Even more importantly, we wanted to hear from them what they needed, and what they expected from us. The importance of this goal is reflected in the title chosen for this report: <u>Listening to the Groups</u>. The Community Development Worker created a meeting plan which outlined the points to be covered with each group. [See Appendix D]

2.4 Networking

As mentioned earlier, new self help groups are forming all the time and we knew our printed lists would not include them all. One important interview question, then, was whether the interviewee knew of any other groups we could contact. We also 'kept our ears open' for any other groups we might hear of as we went about our work.

We were aware that, although the research and development goals of the project were designed to be manageable within the life of the project, our renewed contact with groups on behalf of the Centre might generate further interest and result in expectations for service from project staff that did not, strictly speaking, fall within project guidelines. When this did, in fact, begin to happen, we welcomed it as evidence

of interest in the Centre and did our best to help with information and advice. Serendipitous contacts such as this were documented, and are summarized and discussed in Section 4.2 below.

2.5 Data Collection

In total, approximately 180 groups were identified and attempts were made to contact them all by telephone. If there was no response from a group after at least four phone calls and/or voicemail messages (though often the number was closer to ten), we assumed the group was no longer active or did not wish to meet with us. One or two declined to be interviewed.

The driving motivation for the project was to gather information which would help the Self Help Centre serve the self-help community better. At minimum, we needed to be able to sort out self-help/mutual aid groups from other kinds of groups and programs, because this had policy and strategic planning implications. We wanted also to address the 'nuts and bolts' of operational issues, and that meant we needed to assess the range of resources that existed in the self-help/mutual aid community. In each interview, we asked questions about leadership and agenda-setting, as well as about group resources and organizational support from a sponsoring agency or other institution. Based primarily on leadership and to some extent on purpose or activities, the group was assigned one of five categories — three for mutual aid, one for professionally-led groups, and an 'other' category [See section 2.5.1 below]. Once the interviews were completed and data entry was about to begin, the project team — the two staff and the project supervisor — met to clarify operational definitions and sort out any remaining questions. We chose the term "Type" to refer to the different leadership categories of groups.

2.5.1 Operational Definitions of Group Types

1. PEER ONLY:

Peer-led mutual aid group; no supporting professionals. Group may recruit speakers or occasional advice from related professionals, but the group::professional relationship is episodic, not ongoing and active.

2. PEER PLUS:

Peer-plus groups are member-run mutual aid groups who are actively supported in an ongoing way by 'outside' persons, ie someone(s) committed to the group's mission but who do not share the common life experience which is the group's focus. The person(s) could offer administrative support, medical information or advice, organizational or group functioning advice or help, etc, BUT DOES NOT RUN THE GROUP. In theory, at least, the group could 'fire' the support person if they wanted to.

3. TRANSITIONING:

Groups that were being led by a professional, which are now making a transition to becoming independent, peer-led mutual aid groups, with the professional in a consulting role only -- i.e., they are transitioning from Professionally-led to Peer Plus.⁸ Because there were only three of them in our survey, these were usually, for analytical purposes, grouped together with Type 2 (Peer Plus) groups.

4. MUTUAL AID GROUPS:

This is a summary category created for analytical purposes. It combines Types 1,2 and 3.

5. PROFESSIONALLY-LED:

Support groups run by a professional/paid worker. Members gain support from each other, but the professional facilitator maintains leadership and may not share the common life experience that is the focus of the group.

6. OTHER:

Groups or programs with no direct mutual support component and/or that do not fit criteria for the previous types. This includes, for example, educational programs, self-managed individual programs, umbrella organizations and some nonprofit agencies.

2.5.2 Data Entry and Analysis

We chose to analyze the survey data using a program designed for qualitative analysis, known as Q.S.R. NUD.IST, Power version, revision 3.0.4. Data from each hand-completed questionnaire were transcribed into individual NUD.IST "raw files" (one for each group) by an SPRC staff member or one of the two project staff. Raw files were then converted to "documents" which could be indexed (coded) for analysis within NUD.IST. We felt this would allow us to address both the main questions we began with and others that might arise as we learned more about what the groups were telling us.

⁸ In theory, groups could, of course, be in other kinds of transition, but the ones we identified in this survey were all in the same kind of transition, as it appears in the definition.

3.0 FINDINGS

Of the approximately 180 groups we attempted to contact and interview, we were able to create data files for 159 groups, giving us an approximately 88% sample. An alphabetical listing of all groups surveyed is presented in Appendix E. Groups we tried but were unable to interview are listed in Appendix F. We found that some groups were no longer active; these are listed in Appendix G. At least two contact persons said they were still willing to receive telephone calls, although their groups were no longer active; these are not included among the 159 in our data files, but are listed in Appendix H.

3.1 Description of Groups Surveyed

How were groups identified?

Most of the groups in this survey were identified through our primary source, the directory of Self Help/Support groups from Community Information Service (CIS). The number of groups obtained from each of three sources is shown in Table 3.1.1 below.

Table 3.1.1: GROUPS SURVEYED BY SOURCE OF IDENTIFICATION

Source from which group was identified	Number of Groups Surveyed	Per Cent of Total
Self-help/Support Groups directory CIS, April 1995	112	70
Self Help Network members and former members	14	8.8
Referrals from interviews and other sources	38	24
ALL SOURCES	159*	100

^{*}Some Self Help Network members are listed in the directory, resulting in overlapping categories, so this column is not additive.

How many groups were linked to a sponsoring institution?

Many of the groups were sponsored by an institution or other organizing body, or had links to a larger organization. We thought this information might give us a sense of what services the groups might or might not need. Some also maintain active links with, and receive information and organizational assistance from, parent groups in the United States. For our purposes, a SPONSOR is a larger organization, including provincial or national bodies, that also has other activities besides self-help/mutual aid: fundraising, public

education, advocacy, etc. An UMBRELLA group is an organizing body whose purpose is coordinating the groups, but it does not do the other sorts of things mentioned for sponsors. In practice, these categories were not always clear, so the Sponsor and Umbrella categories are combined in Table 3.1.2 below.

Table 3.1.2: GROUPS WITH LINKAGES TO SPONSOR, UMBRELLA OR U.S. PARENT ORGANIZATIONS

Organizational Link with	Number of groups so linked	Expressed As Per Cent
Sponsor or Umbrella Organization	109/159	69% of surveyed groups
U.S. Parent organization	17/159	11% of surveyed groups
	17/109	16% of linked groups

What types of groups do we have in Hamilton-Wentworth?

In order to develop the "overall picture of ... self-help in our community" [see 2.1 above], it was critical that we be able to distinguish self-help/mutual aid groups from other support, educational and service endeavours. This would allow the Self Help Centre Board of Directors to understand survey information in the context of its implications for policy development, strategic planning, and operational decision-making. The following table shows the number of groups of each type in our survey. [Please refer to definitions in 2.5 above.] The most important observation is that more than two-thirds (69%) are true self-help/mutual aid groups, while a quarter (25%) are professionally-led.

Table 3.1.3: SELF HELP AND OTHER SUPPORT GROUPS IN HAMILTON-WENTWORTH

Group Type		Number surveyed	Per Cent of Total	
Mutual Aid/Self Help Groups	1. Peer only	56	35	
	2. Peer Plus	50	31	
	3. Transitioning	3	1.9	
	4. All Mutual Aid	109	69	
5. Professionally-led Support Groups		39	25	
6. Other		11	7	
TOTAL		159	100	

What common life experiences do the groups focus on?

A self-help/mutual aid group can focus on any life experience that challenges someone to seek out others in similar circumstances and form a group for mutual support and sharing. As a collection, these common experiences can be categorized in various ways, depending on one's purpose. It is perhaps not surprising that as the number of groups grows, so too does the number of categories. While in the eighties Romeder could reasonably describe self-help in Canada with eight categories, a decade later Metropolitan Toronto alone needed sixteen, several of which — Bereavement, Multicultural, and Youth, for example — were not on Romeder's list.⁹ Addiction, and mental and physical health issues, of course, appear in both. Using such sources as a guide, the Hamilton project team reviewed the evidence of our own survey data and compiled a list of twenty areas of "focus" for purposes of this study. [See Table 3.1.5 for the complete list, and Appendix J for definitions of each focus.]

The most common areas of focus among mutual aid groups in our survey were also the most common overall, although the rank order differs. This is shown in Table 3.1.4 following, according to the three major group types: mutual aid, professionally-led, and other. Although the latter two categories are small, results are also expressed as percentages in order to facilitate comparison among types.

⁹ Romeder, Jean-Marie: Self-Help Groups in Canada, Health and Welfare Canada, 1982. pp 14 - 16

¹⁰ Self-Help Clearinghouse of Metropolitan Toronto [now Self-Help Resource Centre of Greater Toronto] The Vutua A c Guice - A Directory of Self-Help/Mutual Aid Groups in Metro Toronto, 1991

Table 3.1.4: FOCUS BY TYPE OF GROUP: SEVEN LARGEST CATEGORIES

Ranked by number of Mutual Aid Groups with that Focus

FOCUS	All Mutual Aid Groups		Professionally- led Groups		Other		TOTAL for this focus	
			n	n = 39		n = 11		n = 159
	#	%	#	%	#	%	#	%
Physical	26	24	9	23	0	-	35	22
Women	21	19	6	15	3	27	30	19
Parenting	19	17	3	8	2	18	24	15
Mental Health	18	17	14	36	2	18	34	21
Addiction	14	13	4	10	1	9	19	12
Disability	11	10	1	3	2	18	14	9
Bereavement	10	9	5	13	1	9	16	10

"Physical " ranks highest both among mutual aid groups and overall, while among professionally-led groups it ranks second. "Mental Health" ranks first among professional groups, second overall, and fourth among mutual aid groups.

Table 3.1.5 presents an overview of existing groups in Hamilton-Wentworth, showing all twenty areas of focus — presented alphabetically to show the range of the topics. All group types are shown, to offer a complete picture of what kind of support is available for each focus.

Of particular interest in this table are the things to be learned by looking at the three types of mutual aid groups: Peer Only, Peer Plus and Transitioning. Some points to note are:

• All three of the Transitioning groups originated as support groups for caregivers of seniors, organized by a nurse in the Department of Public Health. Because of insistent economic constraints on professional resources, the "sustainability" of such groups depends on their becoming more "consumer-driven," with the goal of lessening their need for professional support. For the Self Help Centre, this example may well offer a taste of things to come, as more institutions and agencies find their resources uncomfortably diminished while the people they serve still need groups for support.

¹¹ Telephone conversation with E. Conti, Department of Public Health, July 16/96. Words in quotations are terms frequently used in the Department in relation to demands generated by economic constraints. CN

[Note: In further analysis this category is combined with Peer Plus unless otherwise noted, since it usually does not alter the overall result.]

- For Addiction, Separation & Divorce, and Social Advocacy there are more Peer Only than Peer
 Plus groups. This could be interpreted either as evidence of their greater independence, or of the
 lack of institutional support; what applies to one will not necessarily apply to the others. Twelvestep programs for addictions are the oldest and most enduring model of mutual aid and are justly
 proud of their member-run quality.
- For Abuse the only mutual aid groups are Peer Only, but there are also two Professionally-led and two Other groups.
 For Sexuality, the only two groups are Peer Only mutual aid groups.

Table 3.1.5: FOCUS BY TYPE OF GROUP - OVERVIEW

50000		Mutual Aid	Groups		Profession- ally-led	Other	ALL GROUPS
FOCUS	Peer Only (1)	Peer Plus (2)	Transit. (3)	All MA 1+2+3=(4)	(5)	(6)	4+5+6=(7)
	n = 56	n = 50	n = 3	n = 109	n = 39	n = 11	n = 159
Abuse	3	0	0	3	2	2	7
Addiction	12	2	0	14	4	1	19
Bereavement	1	9	0	10	5	1	16
Crime	0	3	0	3	1	1	5
Disability	5	6	0	11	1	2	14
Employment	1	2	0	3	0	0	3
Ethnocultural	2	5	0	7	0	1	8
Men	1	2	0	3	0	0	3
Mental Health	7	11	0	18	14	2	34
Parenting	10	9	0	19	3	2	24
Physical	11	15	0	26	9	0	35
Seniors	2	1	3	6	2	0	8
Separation & Divorce	7	1	0	8	1	0	9
Sexuality	2	0	0	2	0	0	2
Social Advocacy	6	2	0	8	1	1	10
Suicide	1	1	0	2	1	1	4
Violence & Torture	1	1	0	2	1	1	4
Women	11	10	0	21	6	3	30
Workplace	1	1	0	2	0	0	2
Youth	2	4	0	6	2	2	10

^{*}Columns are not additive, as groups may be identified with more than one focus each .

• For Disability, Parenting, and Women, mutual aid groups are about evenly divided between Peer Only and Peer Plus.

• For Bereavement, Ethnocultural, Mental Health, Physical and Youth, more than half the mutual aid groups are supported by an 'outside' person, ie Peer Plus.

• The three mutual aid groups focused on Crime are for ex-offenders or their families, and all are Peer Plus, ie institutionally supported.

Where do the groups meet?

These results are presented in Table 3.1.6 below. More groups meet in churches than anywhere else, generally at no cost; among mutual aid groups, twice as many meet in churches as meet in the second most common place, the group's own office location. The four most common meeting places for mutual aid groups, in fact, are generally available at no cost to the group, which may explain their popularity.

Table 3.1.6: MEETING PLACE BY TYPE OF GROUP

Ranked by frequency among All Mutual Aid groups

PLACE OF	Mu	itual Aid Gro	ups	Profession-	Other	ALL GROUPS
MEETING	Peer Only (1)	Peer Plus (2)	All MA 1+2=(3)	ally-led (4)	(5)	3+4+5=(6)
	n = 56	n = 50	n = 109	n = 39	n = 11	n = 159
Church etc.	18	14	32	2	2	36
Own premises	8	8	16	5	1	22
Sponsor facility	6	9	15	22	1	38
Home	6	5	11	0	0	11
Self Help Centre	8	2	10	0	1	11
Hospital	6	3	9	2	0	11
YWCA or Women's Centre	3	2	5	2	1	8
Community facility	3	2	5	1	0	6
School	0	3	3	2	0	5
Other places	8	5	13	3	0	16
Unknown or Not Applicable	1	3	4	0	3	7

^{*}Columns are not additive, as groups may list more than one meeting place.

Next in order comes the Self Help Centre; ranked fifth, it is the first meeting place that involves actual cash expenditure for the groups. Full Membership in the Self Help Network currently costs \$75 per year, which then entitles the group to cooperative use of Centre space for group meetings at no additional cost.

Not surprisingly, nearly all Professionally-led groups meet at the sponsoring facility.

What size are self-help/mutual aid groups, usually?

This question was intended to give us an idea of how many people would usually be at a group meeting. Results are somewhat ambiguous, however, probably due to the way it was phrased in the questionnaire. We wrote, "How many members in your group?" -- not anticipating that the number of members was one thing, but the usual number who attended meetings might be another. Further, some respondents gave us figures for local, provincial and even national membership. For these reasons, results for each category refer to local groups and are presented as frequencies only; we are not confident enough of this set of results to warrant percentages.

Table 3.1.7: GROUP SIZE BY TYPE OF GROUP

SIZE OF	Mu	itual Aid Grou	Profession ally-led	Other	ALL GROUPS		
GROUP	Peer Only (1)	Peer Plus (2)	All Mutual Aid 1+2=(3)	(4)	(5)	3+4+5=(6)	
	n = 55	n = 53	n = 108	n = 38	n = 11	n = 157	
Tiny: 2-5 members	2	1	3	2	1	6	
Small: 6-10 members	17	17	34	13	4	51	
Medium: 11-30 members	14	14	28	17	1	46	
Large: >30 members	20	19	39	5	4	48	
Unknown or varies	2	2	4	1	1	6	

^{*} Two groups did not answer this question.

The questionnaire actually had five size ranges to choose from but we found that very few chose the "20-30 members" range, while the ranges on either side were chosen much more often. The responses seemed to make most sense when we combined the "11-20" and "20-30" ranges, so that is how results are presented here. Generally speaking, numbers in the Tiny, Small and Medium categories probably represent actual attendance as well as membership, while the Large category could be showing either attendance or membership — but more often the latter. That said, it is still interesting to see that groups are fairly evenly distributed among Small, Medium and Large. One can be more confident in the observation that for those group sizes, numbers are virtually equal for Peer Only and Peer Plus groups.

How old are the groups?

Results for Mutual Aid groups are shown only in combined form in Table 3.1.8 below; distribution between Peer Only and Peer Plus types is (once again) roughly equal and, therefore, does not add much to our understanding of this question. Percentages for Mutual Aid, Professionally-led and All Groups columns provide points of comparison. Percentages were not calculated in the Other category, since the frequencies are so small.

<u>Table 3.1.8: GROUP MATURITY BY TYPE OF GROUP</u>
Frequency of groups in each age range, showing percentages for Mutual Aid, Professionally-led and All Groups

MATURITY Group has existed for	Mutual A	id Groups	Professio Gro	onally-led ups	Other	ALL GROUPS n = 159		
	n =	109	n = 39		n = 11			
	#	%	#	%	#	#	%	
Infant: < 1 year	10	9	0	-	1	11	7	
Young: 1 - 5 years	41	38	18	46	3	62	39	
Mature: 6 - 10 years	28	26	10	26	3	41	26	
Established: > 10 years	29	27	10	26	4	43	27	
Age Unknown	1	de	1	-	0	2	1.3	

Perhaps the most significant observation from this table is that nearly half the groups in the Region are less than six years old. This is true for Mutual Aid groups (47%) and also for Professionally-led and All Groups (46% each). Among groups older than five years, distribution between Mature and Established is virtually equal. (We hope it is not necessary to point out that "maturity" in this context refers to the groups, not the people in them!)

Groups were asked whether their meetings were open to members only, or whether various other people could attend. Table 3.1.9 below is in two sections, the top showing the overall results and the bottom showing "Others" divided into three categories. Some groups had more than one type of meeting: one for members only, and a general information meeting open to the public, for example. In such cases, both responses were noted, and this explains why the percentages sometimes add to more than 100. In Peer Only, for example, 20% reported meetings for members only, and 88% reported meetings open to others (adding to 108%). This is one characteristic which is quite different between the two subtypes of mutual aid groups: Only 20% of Peer Only groups had meetings for members only, compared to 62% of Peer Plus groups. The similarity this time is between Peer Plus and Professionally-led groups, at 62% and 64% respectively.

Table 3.1.9: OPENNESS OF GROUP MEETINGS BY TYPE OF GROUP

Number and Per Cent of All Groups Surveyed

GROUP MEETINGS ARE OPEN TO		Mutu	ıal Aid	Group	Professio		Other	ALL			
	Peer Only (1) n = 56		Peer Plus (2) n = 53		All MA 1+2=(3)		n-ally-led (4)		(5)	GROUPS 3+4+5=(6)	
									n = 11		
	#	%	#	%	#	%	#	%	#	#	%
Members only	11	20	33	62	44	40	25	64	4	73	46
Some others	49	88	29	55	78	72	12	31	3	93	58
Others: (specified)	n = 49		n = 29		n=	78	n	= 12	-	n =	93
Prospective members	12	24	12	41	24	31	1	8	0	25	27
Invited others	7	14	13	45	20	26	3	25	0	23	25
General Public	44	90	22	76	66	85	9	75	3	78	84

The lower half of the table shows what percentage of groups allowing "Some others" allowed that specific category of others: Prospective Members, Invited Others or General Public. Groups may specify more than one category so, once again, the columns are not additive. The most open are Peer Only groups: 88% said some others could attend, and of those others, 90% included the general public. Once again, this is quite different from the Peer Plus groups who, at 76% open to the general public, are again almost the same as the Professionally-led groups, at 75% open to the public.

What costs are involved in attending a group?

While many groups stated a fee for membership or materials, most did not -- 65% overall. A few of these invite small donations to cover refreshments or material costs.

Nearly half of the Peer Plus groups do charge a fee (47%) while this is true of only about a third of Peer Only groups (32%) and about a quarter of Professionally-led groups (26%). Two Peer Only groups and one Peer Plus group said the fee is optional. One Peer Plus group is free to "patients" while others pay a fee, and one Professionally-led group is free to volunteers of the society. One Peer Plus group and two Professionally-led groups offer bursaries or subsidies. These results are summarized in Table 3.1.10.

Table 3.1.10: PRESENCE OF FEES BY TYPE OF GROUP
Frequency of groups in each category, with per cent of total for each response.

DOES ATTENDING		Mı	itual Ai	id Group	os	Profession ally -led (4)		Other (5)	ALL GI	ROUPS	
MEETINGS INVOLVE A FEE?	Peer Only (1)		Peer Plus (2)		1	lutual lid !=(3)	ual 3)		(6)		
	n =	56	n = 53		n = 109				n = 11	n=	159
	#	%	#	%	#	%	#	%		#	%
YES*	18	32	25	47	43	39	10	26	3	56	35
NO **	38	68	28	53	66	61	29	74	8	103	65
*(yes) with options	2	4	4	8	6	6	3	8	0	9	6
**(no) but invite small donations	0	0	2	4	2	2	1	3	1	4	3

What is the usual fee, when there is one?

The most common amount requested among Mutual Aid groups and All Groups is twenty dollars, as can be seen in Table 3.1.11 below. Seven of these are Peer Plus groups under one umbrella agency but, even without them, twenty is still the most common. Among Peer Only groups, the result is bimodal: four groups ask ten, and four groups ask twenty dollars. Among Professionally-led groups, forty dollars is the most common amount (mode), while forty-five dollars represents the half-way point in the distribution (median). The professionally-led group which states a fee of \$120 allows a participant with limited funds to choose to pay \$60 instead. The one- or two-dollar amounts are often suggested amounts to cover refreshment costs, although the one-dollar fee appearing under Other buys a lifetime membership! Fees up to \$120 can be

membership fees (usually annual) or materials fees -- sometimes both; often the fee entitles the member to a newsletter or similar publication dealing with the group's focus. By contrast, the five-thousand-dollar fee associated with one group is primarily due to fees for legal service involved in adoption.

Table 3.1.11: FEE AMOUNTS BY TYPE OF GROUP
Frequency of groups reporting each amount

FEE AMOUNT	M	utual Aid Grou	Profession ally - led	Other	ALL GROUPS	
\$\$	Peer Only (1)	Peer Plus (2)	All Mutual Aid 1+2=(3)	(4)	(5)	3+4+5=(6)
	n = 18	n = 25	n = 43	n = 10	n = 3	n = 56
1,2 or `nominal'	1	3	4	-	1	5
5,7 or 8	2	2	4	-	-	4
10	4	4	8	1	-	9
15	2	2	4	1	-	5
20	4	14	18	-	1	19
28 or 30	2	1	3	-	-	3
35 or 36	3	-	3	-	_	3
40	-	1	1	3	-	4
45	-	-	-	1	-	1
48,50 or 53	1	-	1	2	1	4
95		-	-	1	-	1
120 [60 optional]	-	-	-	1	-	1
5000	-	-	-	1	-	1

Do the groups meet regularly? How often and when?

This information is available in the database but it was not possible to conduct the analysis in time for preparation of this report. Data has been preserved on disk in the event that further analysis becomes possible or desired in the future.

3.2 Resources Available to Group Members

What resources do groups have to work with in carrying out their goals?

This information would offer a way to assess what other resources might be needed, and how the Self Help Centre might be able to help. In the interviews, we asked about offices and about other resources in terms of both general facilities and information resources. Results are presented in Tables 3.2.1 - 3.2.7 following.

How many groups have offices? How many have other space available?

We asked directly if the group had an office, how satisfied they were with it, and then generally what other facilities the group had. Results are presented in Tables 3.2.1 - 3.2.3 below.

Table 3.2.1: GROUPS WITH OFFICES BY TYPE OF GROUP

Number and per cent of all groups surveyed

	Mutual Aid Groups						1	ssion -led	Other		ALL GROUPS	
DOES THIS GROUP HAVE AN OFFICE ?	HAVE AN		Peer F	Plus 2)	All Mutual Aid 1+2=(3)		(4)		(5)		3+4+5=(6)	
			n = 53		n =	n = 109		n = 39		n = 11		n = 159
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	20	36	37	70	57	52	37	95	8	73	102	64

About half of all self help/mutual aid groups have offices (52%), in contrast to professionally-led groups, who nearly all do (95%). Within Mutual Aid groups, there is quite a difference, though, between Peer Only, about a third of whom have offices (36%) and Peer Plus, where more than two-thirds do (70%). All groups who said they had an office were satisfied with it, with only one exception. That group sells various products to raise funds, and has difficulty finding enough storage space for unsold products.

In Tables 3.2.2 and 3.2.3 below, only frequencies are shown; percentages were not calculated because numbers are small and fairly straightforward.

Among Mutual Aid groups with offices, nearly half reported having an additional meeting room or boardroom available (25/57). A few had lunchrooms or small kitchens -- grouped together here as "eating facilities" -- and a few more mentioned reception areas. Approximately two-thirds of the Professionally-led groups reported additional meeting room space (24/37) and reception areas (26/37), and nearly half reported eating facilities (17/37).

Table 3.2.2: ADDITIONAL ROOM FACILITIES BY TYPE OF GROUP

Number of groups with offices who reported each facility

ADDITIONAL	N	Mutual Aid Gro	ups	Profession ally - led	Other	ALL GROUPS
ROOM FACILITIES	Peer Only	Peer Plus (2)	All Mutual Aid 1+2=(3)	(4)	(5)	3+4+5=(6)
	n = 20	n = 37	n = 57	n = 37	n = 8	n = 102
Meeting space, rooms	13	12	25	24	2	51
Eating facilities	2	4	6	17	1	24
Reception area	4	6	10	26	4	40
Miscellany	5	1	6	1	0	7

What kinds of office equipment do groups have available?

When we asked about facilities, some groups answered in terms of space, others in terms of equipment. Because that question was open-ended, the choice was up to the respondent. It is possible -- particularly in regard to office equipment -- that it might not have occurred to the respondent to mention an item and, consequently, that more groups have some of these resources than are shown here. On the other hand, the apparent predominance of e-mail -- listed here with equipment because it depends on a computer -- over other office equipment is probably an artificial finding, inflated by one set of seven groups all associated with a particular project. Information about these was obtained in a single interview, including the fact that they had access to e-mail through that project's office.

Table 3.2.3: OFFICE EQUIPMENT BY TYPE OF GROUP

Number of groups reporting each type of equipment

	Mu	tual Aid Grou	ps	Profession ally - led	Other	ALL GROUP
OFFICE EQUIPMENT	Peer Only (1)	Peer Plus (2)	All Mutual Aid 1+2=(3)	(4)	(5)	S 3+4+5=(6)
Fax	0	3	3	2	0	8
Photocopier	0	1	1	0	0	2
Computer	0	2	2	0	1	5
E-mail	2	9	11	0	1	12

What information resources do groups have to offer?

When we asked about information resources we sometimes prompted the response, but usually the openended question produced a ready answer. [See Q24 of the questionnaire in Appendix B-1 for the exact wording.] Table 3.2.4 summarizes the responses. An interesting finding here is that more Peer Only than

Table 3.2.4: INFORMATION RESOURCES BY TYPE OF GROUP

Number and per cent (except for "Other") of all groups, ranked by number of Mutual Aid groups

INFORMATION RESOURCES		Mu	ıtual Ai	d Grou	ps		Profession- ally-led		Other		L
	(1)		Peer Plus (2)		All M A 1+2:	id	(4)	(5)	3+4+	5=(6)
	n=	56	n =	53	n =	109	n = :	39	n = 11	n =	159
	#	%	#	%	#	%	#	%	#	#	%
Brochures, pamphlets	34	61	22	42	56	51	10	26	5	71	45
Video & audio tapes, film	23	41	26	49	49	45	28	72	4	81	51
Books	16	29	22	42	38	35	15	38	1	54	34
Print articles, reports	2	4	13	25	15	14	9	23	1	25	16

Peer Plus groups reported having a brochure (61% vs 42%). Overall, about half the Mutual Aid groups listed brochures or pamphlets among their information resources, compared to only about a quarter of the Professionally-led groups (51% vs 26%). Videotapes were listed by nearly half the Mutual Aid groups and nearly three-quarters of the Professionally-led groups (45% vs 72%). Books, and Print articles and reports, were mentioned in similar percentages by Peer Plus and Professionally-led groups (42% vs 38%, 25% vs23%) but considerably less often by Peer Only groups (29%, 4%).

How many groups have a newsletter?

Of the groups who said Yes, some produce their own, others distribute one that they receive from a sponsoring or parent organization. No distinction is made between these in the results presented below, Table 3.2.5. We also asked them how often the newsletter came out, but time did not permit this analysis in time for report writing. As before, data are available on disk for future research.

Table 3.2.5: NEWSLETTER BY TYPE OF GROUP

Number and per cent of groups

DOES THE GROUP		Mu	tual A	id Gro	ups		Profes ally-le		Ot	her	ALL GROUPS	
DISTRIBUTE A NEWSLETTER?		Only		Plus 2)	A	utual id =(3)	(4	1)	(5)	3+4+	5 =(6)
	n =	: 56	n=	= 53	n =	109	n =	39	n =	= 11	n =	159
	#	%	#	%	#	%	#	%	#	%	#	%
YES	26	46	29	55	55	50	5	13	2	18	62	39

About half the Mutual Aid groups distribute a newsletter; Peer Only and Peer Plus groups are just under and just over the halfway mark, but still fairly similar at 46% and 55% respectively. This is in marked contrast to Professionally-led and Other groups, among whom newsletters are much less common (13%, 18%).

In what ways do groups make it easier to access their meetings or services?

For some people, particular things make the difference as to whether they can attend a meeting, understand a presentation or gain access to the benefits and services of the group, and groups have addressed these needs in certain ways. We went through a list of possibilities with each interviewee and invited additional responses as well. Results are presented in Table 3.2.6 following.

Table 3.2.6: ENHANCED ACCESS TO MEETINGS/SERVICES BY TYPE OF GROUP

Number and Per Cent of All Groups Surveyed, Ranked by frequency among Mutual Aid groups

ACCESS TO		Muti	ual Ai	d Grou	ıps			ssion- -led	Other	AL GRO	
MEETINGS OR SERVICES IS ENHANCED	1	Only 1)		r Plus 2)	1	MA =(3)		4)	(5)	3+4+	
BECAUSE OF	n=	56	n:	= 53	n =	109	n =	39	n = 11	n =	159
	#	%	#	%	#	%	#	%	#	#	%
Wheelchair accessibility	39	70	30	57	69	63	30	77	7	106	67
Nonsmoking	39	70	27	51	66	61	31	79	6	103	65
Braille - elevator or information	16	29	20	38	36	33	25	64	4	65	41
Help with transportation	15	27	17	32	32	29	7	18	2	41	26
Help with child care	8	14	20	38	28	26	16	41	4	48	30
Cultural Interpreter	6	11	19	36	25	23	20	51	5	50	31
Electronic mail	2	4	13	25	15	14	0	-	1	16	10
Sign language interpreter	3	5	11	21	14	13	5	13	5	24	15
Phone message service, info line, password, cell phone, etc.	2	4	5	9	7	6	1	3	0	8	5
24-hour access (pager, crisis line)	1	2	4	8	5	5	6	15	0	11	7
Assistive hearing devices	0	-	3	6	3	3	4	10	0	7	4
Other enhancements	7	13	5	9	12	11	2	5	1	15	9

Not surprisingly, perhaps, wheelchair accessibility and a nonsmoking environment are the two most common ways to enhance access. This is true in approximately 60-80% of cases except among Peer Plus groups, where wheelchair accessibility is less and only about half report nonsmoking environments (57%, 51%). Braille elevators or other Braille information are offered by about a third of Mutual Aid groups and by nearly two-thirds of Professionally-led groups (33%, 64%). More than a quarter of Mutual Aid groups offer

help with transportation; Peer Only show just over a quarter, while among Peer Plus groups the number reaches nearly a third (27% vs 32%). Less than a fifth of Professionally-led groups offer help with transportation (18%). Help with child care is offered by about a quarter of Mutual Aid groups taken as a whole, but there is a marked difference between Peer Only and Peer Plus: 18% vs 38%. On this point, there is more similarity between Peer Plus and Professionally-led groups, at 38% and 41% respectively. Cultural interpreters are available among half the Professionally-led groups and about a quarter of Mutual Aid groups (51%, 23%), though this help is more than three times as common among Peer Plus as among Peer Only groups (36% vs 11%). Electronic mail was available among more groups than we obtained e-mail addresses for; in some cases this was because the group's access was through an individual member's personal resources, and the interviewee didn't always know the address. Several mutual aid groups mentioned enhanced telephone service such as an information line, password communications, message service, or access via cell phone. 24-hour access via pager or crisis line was more common among Professionally-led groups than any other type (15%), but not considered necessary by most groups. Assistive hearing devices were offered mainly by groups where hearing was a central focus.

Fifteen groups enhance access to their service in other ways tailored to their particular goals:

- Three offer literature, brochures and/or tapes in several languages
- One mutual aid group and one professionally-led group do personal outreach for people speaking
 other languages: "we identify people that speak other languages"; "Outreach to
 multicultural/multiracial communities; that [we are] here; what are the barriers (language, racism...);
 have done a lot of antiracism work including volunteer training, antihomophobic training".
- Two offered special help with sensory impairment: "provide Deaf Blind services"; "Infrared system sound into light signals, to receiver worn by the person -- assistive listening device".
- One group reported enhancing access by restricting it: "restricted access Women Only service makes it safer".
- Other comments illustrate a variety of enhancements: "service goes to the person, usually;" "breast pump for cleft lip & palate babies"; "newsletter could be taped if necessary"; "dances are held at the Club Continental".

3.3 Satisfaction with the Group

In the course of learning about group characteristics and resources, we began to get a sense of how the group was going. We also asked the question directly, "Are you satisfied with the way your group is functioning right now?" and invited those who said No to amplify their comments. Interestingly, a number of respondents said that they were satisfied, then went on — uninvited — to amplify or express concerns. Table 3.3.1 summarizes the Yes and No responses and how many went on to express concerns following each response.

The outstanding observation here is that more than 80% of all respondents said they were satisfied with how the group is going, in all types of groups. Peer Only and Peer Plus groups were 3% on either side of the percentage for All Mutual Aid groups (81%, 87%, 84%). Professionally-led groups responded even more positively: 35/37 (95%) said they were satisfied. Sixteen Mutual Aid groups expressed some dissatisfaction with the group and all but two amplified that response; only eight of the eighty-five who said they were satisfied went on to comment.

Table 3.3.1: GROUP SATISFACTION BY TYPE OF GROUP

Number and per cent of groups who responded to this question

		N	futual /	Aid Gro	oups		Profes ally-		Other	AL GRO	LUPS
SATISFIED WITH HOW	Feel Olliv		Peer (2			ual Aid =(3)	(4)	(5)	3+4+	5=(6)
IS GOING	n =	53	n =	n = 48		n =	37	n = 7	n=	145	
NOW?	#	%	#	%	#	%	#	%		#	%
YES	46	87	39	81	85	84	35	95	6	126	87
NO	7	13	9	19	16	16	2	5	1	19	13
Yes although*	5	-	3	-	8	-	1	-	1	10	-
No because*	5	-	9	-	14	-	1	-	1	16	-

^{*} Groups from within Yes or No categories who amplified that response with comments.

What concerns did the groups express in this context?

Concerns expressed in the context of satisfaction/dissatisfaction with the group can be summarized under the five topics shown Table 3.3.2. For each topic and group type, the table shows how many had said Yes or No to the satisfaction question and how many together expressed that concern. Among All Mutual Aid groups, for example, ten groups expressed concerns about recruitment, four of whom had said Yes and six of whom had said No.

Table 3.3.2: TOPICS OF CONCERN BY SATISFACTION WITH GROUP AND GROUP TYPE

Ranked by number of All Mutual Aid groups expressing each concern

	А	RE YO	U SATI	SFIED	WITH TI	HE WA	Y YOUR	GROU	P IS G	OING	NOW	?	
CONCERNED ABOUT:		M	utual A	id Gro	ups		Profes		Oth	ner		ALL GROUPS	
	Peer Only (1)		Peer Plus (2)		AII MA 1+2=(3)		ally- (4	(4)		5)	3+4+		
	yes	no	yes	no	yes	no	yes	no	yes	no	yes	no	
Recruitment	3	3	1	3	4	6	1	1	1	1	6	8	
	6		4		1	0	2		2	2	1	4	
Services to	-	_	2	5	2	5	0	1	-	-	2	6	
members	-			7		,	1		-		8	3	
Group	1	1	0	4	1	5	0	1	1	0	2	6	
functioning		2	4	4	6	3	1		1		8	3	
Difficulties with	1	1	0	1	1	2	-	-	1	0	2	2	
unding		2		1		3	-				4	1	
Relationship	-	-	1	2	1	2	-	-	-	-	1	2	
with doctors		-		3		3	_		-		3		

Comments on each topic by those not satisfied (No) and satisfied (Yes) with group:

RECRUITMENT

Mutual Aid, not satisfied:

- >New members -- recruitment is needed
- >More volunteers would help to carry out tasks
- >Lack of new members
- >Recruitment of new members
- >Need rejuvenation, 'young blood'
- >We are just starting up; need to recruit more members

Mutual Aid, satisfied:

- >Looking for more members
- >Transition time: changes due to health of older executive who are leaving; need more younger people to do work; advertising for volunteer teams to go into schools anyone interested & willing to speak on behalf of [group]
- >Recruiting more members
- >Would like to see Mountain group

Professionally-led and Other, not satisfied:

- >Would like to be used more
- >Would like to see more attendance; more animation, support ...

Professionally-led and Other, satisfied:

- >We would like more people participating; we would like more referrals
- >Board erosion

SERVICES TO MEMBERS

Mutual Aid, not satisfied:

- >Need to adjust to an employment paradigm shift: more self-employment; bartering; continuous reeducation; values adjustment; lifestyle adjustment; new style of networking (who do you know PLUS demonstrate competence)
- >Need more than peer support would like an ADVOCATE to deal with 'the system', eg when kids get in trouble with the law
- >Meetings irregular due to preparations involved in hosting 2 conferences
- >Would like our information in ALL ENT doctors' offices
- >Trying to get reorganized want new coordinator

Mutual Aid, satisfied:

- >Don't want to get much bigger-would have to split into 2 or refer to other existing groups
- >Biggest challenge is to know about hospital admissions -- dependent on hospital staff to notify [group]; hospitals need to know

Professionally-led, not satisfied:

>Much more that we could be doing, e.g., shift emphasis from patient only to patient AND family; post-hospitalization lifestyle management; see it as coming with management restructuring from middle management to more front-line workers; have sent questionnaire to families to see what they're looking for, build in response to that.

GROUP FUNCTIONING

Mutual Aid, not satisfied:

- >We are bringing speakers—who suffer [same condition] --to improve the group meetings
- >Involvement
- >Morale
- >Need rejuvenation, "young blood"
- >Needs to be revived

Mutual Aid, satisfied:

>Grow-up

Professionally-led and Other, not satisfied:

- >Would like to see more attendance; more animation, support ...
- >Board erosion

DIFFICULTIES WITH FUNDING

Mutual Aid, not satisfied:

- >Lack of funding
- >We lost 100% funding, and we are trying other ways of funding Re:United Way emergency funding
- >Funding cutbacks mean participants are having to justify their time for meetings, harder to get away Other, not satisfied:
- >Cuts of funding and support

RELATIONSHIP TO DOCTORS

Mutual Aid, not satisfied:

- >Need to increase education of physicians about Lupus
- >Would like to see doctors more sympathetic -- people are often fed up

Mutual Aid, satisfied:

"Glad for what you're doing -- survey -- because medical people need to know"

3.4 Experience with the Self Help Centre

Having learned about the groups themselves and how they were going, we then wanted to learn how they viewed the Centre, what their particular needs were, and what they wanted the Centre to do for them.

How many groups know about the Self Help Centre?

More than two-thirds of all groups we surveyed had heard of the Centre, with little variation across group types, as can be seen in Table 3.4.1 below.

Table 3.4.1: KNOWLEDGE OF THE SELF HELP CENTRE BY TYPE OF GROUP

Number and Per Cent of All Groups Surveyed

DO YOU KNOW		Mutu	ual Aid	Group	s			essio ly-led	Otl	ner	AL GRO	
ABOUT THE SELF HELP CENTRE?	Peer Only (1)			Plus 2)	All 1+2:		(4)		(5)		3+4+5=(6)	
	n =	56	n=	53	n =	109	n = 39		n = 11		n = 159	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, have heard about the SHC	38	68	37	70	75	69	27	69	7	64	109	69

What image or impressions do people have of the Self Help Centre?

Table 3.4.2 below summarizes the responses to this question. The most common impression was expressed in words such as "positive," "useful," or "helpful." Among professionally-led groups, this accounted for nearly two-thirds of responses to this question (63%). Peer Only and Peer Plus groups responded almost identically, so results for Mutual Aid groups are presented as a whole here. Again, the most common impression among Mutual Aid groups was generally positive (39%). About a third of them responded by referring to some past or current link with the Centre, or a service they were receiving, without adding a positive or negative value to it (16% + 12% + 5% = 33%). About a fifth of responses from Mutual Aid groups identified problems that the Self Help Centre needs to work on in order to improve its service.

Table 3.4.2: IMAGES OF THE SELF HELP CENTRE BY TYPE OF GROUP

Number and per cent of those who had heard of ('know about') the SHC

	ESSIONS or IMAGE of the F HELP CENTRE	All Mut		1	ionally- ed !)	Other (5)	ALL GROUP: 3+4+5=(6)		
		n =	75	n =	27	n = 7	n = 109		
		#	%	#	%		#	%	
Positive fruitful .	, good,useful, helpful,	29	39	17	63	3	49	45	
meeting; s start of SI	ast link - eeting; service inquiry; involved at art of SHC; received help to start H group		16	1	4	0	13	12	
	link - Self Help Network know someone here	9	12	0	-	1	10	9	
SHC si	ervice - lace, voicemail, photocopy	4	5	1	4	0	5	5	
SHC needs	Combined - suggestions, problems	14	19	4	15	0	18	17	
to work	to Can't afford membership		ansit.)		1	0		5	
on			4		1		5		

A number of positive comments were amplified, as shown in the following examples:

Peer Only:

- >Very positive we would like use some meeting rooms in the future
- >It is a good thing for the community
- >A good idea, something like this is very needed in the community
- >Very needed in the community
- >Excited, pretty nice here
- >Keep up the good work

Peer Plus:

- >It is good for the community
- >It is a good thing
- >Good, central, bright, accommodating...

Professionally-led:

- >Needed in the community
- >It is an excellent resource for the community; we are interested in considering a group running there.
- >A centre for the community (2 groups)

Other:

>Good idea; glad someone's using the old school

What suggestions or problems did groups identify for the Self Help Centre to work on?

Comments identifying areas for the Self Help Centre to work on include:

MEMBERSHIP FEE

Transitioning to Peer Plus:

- >Fee is not affordable for us
- >We could not afford the membership fee
- >We can't afford membership

Peer Plus:

>We were members but we could not afford it -- we meet once a year

Professionally-led:

>We could not afford the membership fee

VAGUE OR INACCURATE IMPRESSIONS

Peer Only:

- >We have read articles in the paper
- >We don't have any impression, just know that it is there
- >Heard a little about it
- >We thought it was just for housing
- > It is an interesting concept

SELF HELP CENTRE SERVICES

Peer Plus:

- >Hope it will be functional soon; it is taking such a long time to make it work
- >Found it cold -- went to get book
- >Problem: ramp & lift are "not for" one particular person in group, but quite good, cheap
- >Frankenstein -- looks like a body, has unmatched parts (made of gathered parts), but no soul.

HOWEVER, the CONCEPT of self help is the greatest thing we have now. Need to: get the stitches out; get a nervous system; become new; have the Spirit breathe life into the Centre!; get electronic connection Professionally-led:

- >Did not get a lot of support from them
- >Grassroots -- very important! Attitude of willingness to help; underutilized; TONS of potential!

What past links with the Self Help Centre did people mention?

The most positive comments refer to someone who helped them get their group started (2 groups). The others leave open the question of whether the experience was positive or left something to be desired:

Peer Only:

- >We just went to inquire about the facilitators training
- >One of our board members went to the meetings at the beginning
- >We were involved with The Prevention Network
- >I was involved the first year when they opened but they were offering nothing we needed at that point
- >We were involved in the beginning; Geraldine Copps; however we did not fit in the category

Peer Plus:

- >We received info when it was starting up (2 groups)
- >We went to a meeting a couple of years ago
- >We were involved in the Self Help Network
- >From the beginning of 1993 we were offered office space

Professionally-led:

>We were involved at the beginning of the Network

How many groups have used the Self Help Centre?

These results are summarized in Table 3.4.3 below. Among Mutual Aid groups, only 13% report ever having used services of the Self Help Centre, and only 10% say they are currently using them. This means that 90% of the surveyed mutual aid groups see themselves as not being served by the Self Help Centre. Three of the four Peer Plus groups who ever used the Centre now no longer do. Of the ten Peer Only groups who ever used the Centre, however, all ten are also current users.

Table 3.4.3: SELF HELP CENTRE EXPERIENCE BY TYPE OF GROUP

Number and Percent of groups surveyed who have ever used and currently use SHC, number who no longer use SHC

EXPERIENCE		Μι	ıtual Ai	d Grou	ps		Profession-	Other	ALL GROUPS	
with the SELF HELP CENTRE	Peer (1	-	1	Plus 2)	l l	MA =(3)	ally-led (4)	(5)	1	5=(6)
	n =	56	n =	53	n =	109	n = 39	n = 11	n =	159
	#	%	#	%	#	%	#	#	#	%
EVER used	10	18	4	8	14	13	2	1	17	11
CURRENTLY use SHC	10	18	1	2	11	10	0	1	12	8
NO LONGER use	()		3		3	2	0		5

What is the focus of groups who use the Self Help Centre?

Of the twenty topics which are the focus of groups in the survey, fourteen are represented among groups who <u>ever</u> used the Centre, as shown in Table 3.4.4 below, and six are not (listed in the bottom row).¹² Mental Health, Social Advocacy and Women have more groups than the other topics, among both current users (three groups each) and those who ever used the Self Help Centre (four, four and five respectively).

¹²While this report was being written, two Anonymous groups began meeting at the Centre, which would move Addictions into the list of topics represented among user groups.

Table 3.4.4: FOCUS OF GROUP BY USAGE OF SELF HELP CENTRE

	Groups w	ho reported h	aving used th	e Self Help C	entre
FOCUS	Ever	Currently	No Longer	Pas	t Uses
				Meetings	Voicemail
	n = 17	n = 12	n = 5	n = 15	n = 5
Abuse	2	1	1	2	1
Cnme	1	0	1	1	0
Disability	3	2	1	2	0
Employment	1	1	0	1	0
Ethnocultural	1	1	0	1	0
Mental Health	4	3	1	3	1
Parenting	3	2	1	3	1
Physical	1	0	1	1	0
Seniors	2	0	2	2	0
Social Advocacy	4	3	1	3	1
Violence & Torture	1	0	1	1	0
Women	5	3	2	5	1
Workplace	2	2	0	2	2
Youth	1	1	0	1	0
NEVER USED (by category)	Addiction Sexuality	Bereavement Suicide	Men Separation	on & Divorce	

Columns are not additive, as groups may be identified with more than one focus each.

Of the fourteen with groups who ever used the Centre, ten are represented among <u>current</u> users, four of them by the same number of groups: Employment, Ethnocultural, Workplace and Youth (five groups). Five other topics have lost one group each, while women's groups have been reduced by two, from five to three. Four topics are no longer represented among current users: Crime, Physical, Seniors and Violence & Torture (five groups).

Three times as many groups report having used the Centre in the past for meeting rooms as for voicemail (15 vs 5).

What types of groups used, and still use, which services of the Self Help Centre?

As mentioned earlier, the most common use of the Self Help Centre is for group meetings; voicemail is the second most common. Most surveyed users of Self Help Centre services are Mutual Aid groups (14/17). Two Professionally-led groups used meeting rooms in the past, and one Other group rents office space. Among Mutual Aid groups, use of meeting rooms has dropped from thirteen to seven, a decrease of six groups, while use of voicemail has increased by one, from five to six groups. One Peer Only group also rents office space in the Self Help Centre.

Table 3.4.5: USE OF SELF HELP CENTRE SERVICES
by survey groups who have EVER used the Self Help Centre

SELF HELP		M	utual Aid Grou	ps	Pro-led & Other	ALL GROUPS
GROUPS		Peer Only (1)	Peer Plus (2)	AII MA 1+2=(3)	(4), (5)	3+4+5=(6)
		n = 10	n = 4	n = 14	n = 3	n = 17
PAST	Meeting rooms	9	4	13	2	15
	Voicemail	4	1	5	0	5
CURRENT	Meeting Rooms	6	1	7	0	7
	Voicemail	5	1	6	0	6
	Office space	1	0	1	1	2

How satisfied are users with Self Help Centre services?

Six Peer Only groups and one Other group said they currently use the services of the Self Help Centre, and all said their needs were being met. The one Other group amplified this response with, "has been a pleasure to work with Don and Gloria and the SPRC".

Table 3.4.6 SELF HELP CENTRE AS MEETING NEEDS BY TYPE OF GROUP among CURRENT users of the Self Help Centre

Are SHC	M	lutual Aid Gro	Other	ALL GROUPS		
services meeting your	Peer Only (1) Peer Plus (2)		All MA 1+2=(3)	(5)	3+5=(6)	
needs?	n = 6	n = 0	n = 6	n = 1	n =7	
Yes	6	0	6	1	7	
No or not sure	0	0	0	0	0	

One Professionally-led group that had used the Self Help Centre extensively in the past, but does no longer, explained why:

- 1. MONEY! Couldn't keep paying -- now have free space in our building
- Inconvenience lugging handouts, even though some storage space available at Self Help Centre
- 3. Auditorium very large, echoey; kitchen very frustrating [inadequate facilities ...] that's why Boardroom is better.

How do groups rate their satisfaction with the services of the Self Help Centre?

An interesting thing happened with this question: 28 people answered it although only 17 reported ever having used the services of the Centre; 25 were Mutual Aid groups, although only 14 had ever used the SHC. Results are summarized in Table 3.4.7 following.

Most groups were satisfied or very satisfied: 25/28 groups overall, and 20/25 Mutual Aid groups. None of the four neutral groups amplified this response, so we have no indication of their reasons. The only clue to the one dissatisfied response, from a Peer Only group, was a reference in another part of the interview to the early days of the Centre: ">we were involved in the beginning; Geraldine Copps; however we did not fit in the category".

Table 3.4.7: SELF HELP CENTRE SATISFACTION RATING BY TYPE OF GROUP

Ratings from 2 (dissatisfied) to 5(very satisfied)*

HOW SATISFIED	Muti	ual Aid Group	s	Profession- ally-led	Other	ALL GROUPS
ARE YOU WITH THE SERVICES	Peer Only (1)	Peer Plus (2)	All MA 1+2=(3)	(4)	(5)	3+4+5=(6)
OF THE SELF HELP CENTRE?	n = 14		n = 25	n = 2	n = 1	n = 28
Very satisfied	4	0	4	0	1	5
Satisfied	8	8	16	2	0	18
Neutral	1	3	4	0	0	4
Dissatisfied	1	0	1	0	0	1

^{*}No group responded with a rating of 1 - very dissatisfied.

What additional services/facilities do groups need?

This question -- similar to the one about enhanced access -- was presented as a list of possibilities to which respondents were to answer Yes, No or Not sure, and then add anything else that came to mind [Refer to Q40 in questionnaire, Appendix B-1]. "Yes" answers are summarized below in Tables 3.4.8 and 3.4.9.

More groups need office equipment than anything else; next they need space, then library resources, then various other needs. Clearly, Mutual Aid groups are needier than Professionally-led groups; of the latter, only two groups said they need office equipment, space, or library or other resources (2/39, about 5%). By contrast, nearly a quarter of the Mutual Aid groups need some item of office equipment, about a fifth have space needs, and another fifth need media resources or other items. More Peer Only than Peer Plus groups need a computer for typing and data processing, voicemail, a place to hold self help meetings, and library resources. More Peer Plus than Peer Only groups need a place for fundraising. On other items, the two types of Mutual Aid groups seem about the same. Among Other groups, the level of need is similar to that in Mutual Aid groups: 3/11 need office equipment (about 27%) and 2/11 need space (about 18%).

Table 3.4.8: GROUP NEEDS BY TYPE OF GROUP

Number of groups, ranked by frequency among All Mutual Aid groups

		Mutu	al Aid G	roups	Profession- ally-led	Other	ALL
What groups say they NEED BEYOND what they have now		Peer Only (1)	Peer Plus (2)	All MA 1+2=(3)	(4)	(5)	3+4+5=(6)
		n = 56	n = 53	n = 109	n = 39	n = 11	n = 159
At least one	need (any kind)	14	17	31	2	3	36
One or more items		12	13	25	2	3	30
Office equipment needs	photocopier	11	9	20	1	2	23
	fax	8	9	17	0	2	19
	computer - electronic networking	6	5	11	2	1	14
	computer - typing & data processing	6	3	9	1	0	10
	voicemail	5	2	7	1	1	9
Space needs	One or more purposes	9	11	20	2	2	24
	for fundraising	7	9	16	1	2	19
	for Self Help meetings	9	5	14	1	1	16
Library Reservices: be	ources - any media ooks, articles, manuals,	9	6	15	1	0	16
Other needs	3	3	4	7	1	0	8

Specific other needs identified by the groups are as follows:

Peer Only:

- >Transportation-vehicle
- >Office help
- >Hoping to speak to interested groups; would like MD-type--e.g., College of Physicians--who would listen--but not yet--don't seem to want to hear

Peer Plus:

- >Dedicated organization phone line
- >Workshop space, especially for handicapped women immigrants
- > Possibly larger office space
- >Most important -- how to identify patients with [this condition] -- how can support group referral become part of general health care approach? Integration of services; Directory -- CRUCIAL;

Long discussion about growth of self help in current cutback climate, need to integrate other related groups around shared issues

Professionally-led:

>Would love a larger room for volunteer training

Which focus areas have the most needy groups? Which have the fewest needy groups?

We have seen in the foregoing table that most of the groups expressing needs in our survey are Mutual Aid groups. We wondered whether the focus of the group's attention -- the common life experience that draws its members together -- might be related in some way to needs. Table 3.4.9 below shows the four categories of needs expressed, the number of groups expressing that need (n=x), and how many groups with a particular focus said Yes, they have that need. The three columns on the right show how many of the groups we interviewed said they needed something -- that is, they said Yes to any one of the four smaller categories; these responses are shown under the Any Needs column. For example, we interviewed seven groups dealing with Abuse, three of whom expressed needs; expressed in percentage terms, this would indicate that 43% of groups dealing with Abuse need something. The same calculations were done for all focus areas in order to provide a basis for comparison (recognizing that the numbers are small and therefore one cannot, statistically speaking, be confident that the percentages are "true"). These percentages are shown in the last column, "Groups who said they needed something (%)".

In those terms, then, it could be said that Workplace Safety, Employment, and Social Advocacy show the greatest need, at 100%, 67% and 60% respectively. The least needy groups are those focusing on Crime, Men and Sexuality, none of whom said they needed anything; these are followed by Mental Health and Addiction, at 6% and 11% respectively.

Another way to assess overall neediness is to look at how many <u>categories</u> of need were expressed by groups with a given focus. According to percentage alone, Bereavement appears slightly needier than Disability (56% compared to 50%) but Bereavement shows needs in only two categories while Disability shows needs in all four. With similar percentages of <u>any</u> need but needs in more categories, Disability could arguably be said to be 'needier' than Bereavement. By thus combining the two methods, one can very crudely assess the level of neediness among groups with a given focus. Table 3.4.10 below shows the ranked responses for each focus according to percentage of any need alone, and then by number of categories of need expressed and percentage expressing any need.

Table 3.4.9: GROUP FOCUS BY NEEDS BEYOND CURRENT RESOURCES

Number of groups, of all who expressed that need, and percent of all groups surveyed who expressed any need

FOCUS	What gi	roups say they they ha		eyond what ALL GROUPS				
	Meeting Space	Office equipment	Library resources	Other needs	ANY NEED	Interviewed #	Groups who need something (%)	
	n = 24	n = 30	n = 16	n = 6	36	159	23	
Abuse	3	3	1	1	3	7	43	
Addiction	0	1	0	1	2	19	11	
Bereavement	7	9	0	0	9	16	56	
Crime	0	0	0	0	0	5	0	
Disability	3	5	2	1	7	14	50	
Employment	2	2	2	1	2	3	67	
Ethnocultural	1	1	1	1	2	8	25	
Men	0	0	0	0	0	3	0	
Mental Health	1	1	1	2	2	34	6	
Parenting	4	5	5	0	7	24	29	
Physical	3	3	4	3	7	35	20	
Seniors	2	3	2	0	3	8	38	
Separation & Divorce	2	2	2	0	2	9	22	
Sexuality	0	0	0	0	0	2	0	
Social Advocacy	5	6	4	2	6	10	60	
Suicide	0	1	0	0	1	4	25	
Violence & Torture	1	1	0	1	1	4	25	
Women	4	4	3	3	7	30	23	
Workplace safety	2	2	2	0	2	2	100	
Youth	2	2	0	0	2	10	20	

^{*}Columns and Rows are not additive, as groups may be identified with more than one focus or express more than one need each.

Table 3.4.10: GROUP FOCUS BY TWO WAYS OF RANKING NEEDINESS

FOCUS	Percent of groups expressing any need (need something)	Rank* based only on % with any needs	Number of categories of need	Adjusted Rank* based on # categories of need and % with any needs	
Employment	67	2	4	1	
Social Advocacy	60	3		2	
Disability	50	5		3	
Abuse	43	6		4	
Ethnocultural	25	10		5	
Women	23	12		6	
Physical	20	14.5		7	
Mental Health	6	17		8	
Workplace Safety	100	1	3	9	
Seniors	38	7		10	
Parenting	29	8		11	
Violence & Torture	25	10		12	
Separation & Divorce	22	13		13	
Bereavement	56	4	2	14	
Youth	20	14.5		15	
Addiction	11	16		16	
Suicide	25	10	1	17	
Crime	0	19	0	19	
Men	0	19		19	
Sexuality	0	19		19	

^{*} Groups with the same percentage (and # categories of need) are given the same rank, obtained by adding the ranks that all those groups would occupy, then dividing by the number of those groups. The three groups with percentages of 0, for example, occupy ranks 18, 19, and 20, which sums to 57, divided by 3 produces a rank of 19.

either method, and Ethnocultural, Workplace Safety and Seniors rank 10 or higher by either method; these seven, then, would appear to be the most needy. In addition to the three focus areas in which the groups expressed no needs at all. Separation & Divorce, Youth and Addiction seem to be the least needy, showing ranks of 13 or lower by either method.

What do groups want from the Self Help Centre?

This may be the most important question we asked. In keeping with our dual goals of development and research, we invited the groups to share their expectations so that Self Help Centre planning and policy development could be based on information from the constituency it is here to serve. The precise wording of the question was, "What (if anything) would you like the Network/Centre to offer? [workshops, SH Fair ...]" Results are presented in Table 3.4.11 below. The row of "n = x" shows numbers of groups who responded

Table 3.4.11: WHAT GROUPS WANT FROM THE SELF HELP CENTRE BY TYPE OF GROUP

Number of groups who want something, ranked by frequency among All Mutual Aid groups

		Mutu	al Aid G	roups	Profession- ally-led	Other	ALL	
WHAT GROUPS WOULD LIKE THE SELF HELP NETWORK / CENTRE TO OFFER		Peer Only (1)	Peer Plus (2)	All MA 1+2=(3)	(4)	(5)	GROUPS 3+4+5=(6)	
		n = 48	n = 48	n = 96	n = 34	n = 8	n = 138	
Space - mee	ting rooms, etc.	20	26	46	16	4	66	
Networking	in general	18	18	36	6	2	44	
	electronic	6	5	11	2	1	14	
Information	in general	15	12	27	14	0	41	
	about other groups	4	3	7	2	0	9	
	calendar of events	1	2	3	3	0	6	
Group devel	opment ing, workshops)	18	9*	27	2	1	30	
Referral sen	rice ringhouse services)	13	11	24	17	2	43	
Self Help Fa	ir	8	9	17	1	2	20	
Directory of	Self Help Groups	5	9	14	7	2	23	
Publicity abo	ut the group	3	3	6	9	1	16	
Accept from Cultural sens	the group: sitivity training	0	5	5	0	1	6	
Speakers, sp	peakers' bureau	3	1	4	0	0	4	
Other wants		0	2	2	0	0	2	

^{*}Includes 2 groups in transition from being professionally-led to peer-led.

to this question; some groups did not respond, so numbers are slightly lower than the number interviewed. The question was open-ended, but occasionally we would add the prompt contained in the brackets. Similar responses -- mostly one word or short phrases -- were then grouped during analysis as shown. For simplicity's sake, responses to this question are referred to as "wants" in order to distinguish them from "needs" which were presented earlier in Tables 3.4.8 - 10 inclusive.

Most of the groups had heard of the Centre and view it favourably, so it is not surprising that "Space" was the most common response among all group types. Networking, Information, Group Development (which includes workshops, facilitator training and other group development assistance) and Referral Service were

the next highest among Mutual Aid groups and overall, although the order is different for All Groups.

One interviewee who supports several mutual aid groups for immigrant women had a very interesting response to the question. When asked what we could offer them, she responded that actually they would be interested in offering <u>us</u> something: they would like to offer cultural sensitivity training to anyone involved with the Self Help Centre, in order that its services and activities might be more inviting and accessible to the growing and varied immigrant population in our community.

Not surprisingly, Mutual Aid groups were much more interested in a Self Help Fair than other groups. A Directory of Self Help Groups, on the other hand, was of considerable interest to all types of groups. This can be seen more clearly in Table 3.4.12, which takes the most common wants from Table 3.4.11 and summarizes them by Mutual Aid and all other groups (Professionally-led plus Other), showing both number and per cent of responses. Although twice as many Mutual Aid groups as other groups said they want a Directory, the proportion is actually higher among Professionally-led & Other (21% vs 15%). Interest in a referral service is also very high among Professionally-led & Other groups (45%), ranking a close second for that type.

Table 3.4.12: WHAT MOST GROUPS WANT FROM THE CENTRE BY TYPE OF GROUP (SUMMARY)

Number and per cent of groups who want something, ranked by frequency of general wants among Mutual Aid groups

WHAT MOST GROUPS WOULD	Mutual Aid Groups n = 96		Professionally-led & Other		n = 138	
LIKE THE SELF HELP NETWORK / CENTRE TO OFFER						
NETWORK / CENTRE TO OTTER	#	%	#	%	#	%
Space - meeting rooms, etc.	46	48	20	48	66	48
Networking in general	36	38	8	19	44	32
Information in general	27	28	14	33	41	30
Group development	27	28	3	7	30	22
Referral service	24	25	19	45	43	31
Self Help Fair	17	18	3	7	20	14
Directory of Self Help Groups	14	15	9	21	23	17
Publicity about the group	6	6	10	24	16	12

Although most responses were just a word or short phrase, others were more expansive, as the following selections will show.

SPACE

Peer Plus (perspective, from a professional facilitator who hoped to see the group make the transition):

>Safe place to meet as next step in their healing, when ready to leave safety of [current location] -- e.g., confidentiality, friendliness, accessibility. ['Graduates' of this group were beginning to meet on their own, with the facilitator on stand-by in the next room]

Peer Plus:

>Place to hold SH meetings for new smaller groups, weekdays, eves

NETWORKING

Peer Plus:

>Networking; general meetings with other SH groups — the idea here is to meet once a month with contacts from the rest of the SH groups for information exchange and networking

GROUP DEVELOPMENT

Peer Only

>Training with outreach and other related training; counselling training

Peer Plus (transitioning*):

- >Info how to grow in your group*
- >Workshops; support for and promotion of the groups *

- >Recruitment skills workshops
- >Educational activities; training for facilitators

Professionally-led:

>If I had known a couple of years ago, might have helped start a group for two interested, motivated people; they would have liked Facilitator Training

>Workshops for facilitators; we would be interested in participating in the facilitators workshop

REFERRALS

Peer Plus:

>Generic reference material on e.g., group homes, facilities; referrals -- how to access the health system, how to find the help you need -- kids "fall between the cracks", MOH, CSS -- who do you talk to?

PUBLICITY

Peer Only:

>Advertising about the self-help groups; educating people about self-help groups and the illnesses they deal with

>Information about our groups (2 groups)

Peer Plus:

- >Information about us
- >Info about us for the public
- >Publicity about the groups; what they offer

Peer Plus (perspective, from a professional facilitator who hoped to see the group make the transition):

> Help with advertising -- getting the word out; preparing print materials

Professionally-led:

- >Information about this program disseminated in the community
- >Help to publicize [group]; put us on your fax list we'll put you on ours, too

OTHER WANTS

Peer Plus:

- >Funding -- money
- >Data systems
- >Evening hours
- >More welcoming, friendly come out from behind desk; needs a lot of publicity

3.5 Other Issues

At the conclusion of each interview, we asked if there was anything else the interviewee would like to mention. Seventeen respondents answered affirmatively, of whom thirteen were from Mutual Aid groups. Most of the comments focused on self-help/mutual aid or related community needs. Grouped by topic and group type, the comments are listed below.

SELF HELP CENTRE SERVICES

Peer Only:

- > Just one thing: the walls allow "sounds" to go from one room to the other (rooms 4a & 4b) which distracts and is an issue of confidentiality
- > We do not want to give more info because of the anonymity of the group-they do not want to be identified >Keep up the good work

Peer Plus:

- > Ongoing updates
- >It would be good if the Centre could offer resources on How to Start self help groups
- > Important to get new directory to:
 - 1-GP's offices, MD's still trusted, good marketing strategy; pressure on MD's, nurses, social workers is great, would be grateful for the help of this SH directory
- 2-Multicultural, ethnic groups, e.g., Multicultural Centre, Mayor's Race Relations committee interviewee has contact— SHC would have credibility, they would trust our information;
- 3-Churches

Professionally-led:

>We want to know more about charges at the SHC

NEED FOR NEW GROUPS OR OTHER SERVICES

Peer Only:

- >We would like to find a self-help group for Multiple Personality that is not professionally-led
- >Concern over gap in services: no facility that houses women [with substance abuse problems] and children! Don't want to involve CAS because there's no guarantee that the woman will get the child back

Peer Plus:

- >Immigrant women with health problems -- are less likely to be in an illness-focused group -- could we [SHC] facilitate ? Especially self-help and health
- >Need referral services for pregnant users of alcohol or other drugs -- where to get help; sometimes they are users already, with no periods due to 'using' -- THEN they get pregnant but don't know it.

Professionally-led:

>See need for groups for disempowered; see gaps, especially for younger women .. Could `run a self-help group on...'

Other:

> May be starting a group around "flashbacks" ~post-traumatic stress disorder ...

FUNDING, CUTBACKS

Peer Only:

>We would like to learn how to get funding since every expense so far is from our own pocket Peer Plus:

>Volunteering is the way to go, especially with current cutbacks

MISCELLANEOUS

Peer Plus:

- > National Charter; looking into Provincial Charter; have Advisory panel, would like to expand, add representatives from Law Society, police
- > We encourage individuals to feel and experience the sense of community and take responsibility for themselves and their welfare

Professionally-led:

>May be interested to read Open Minds, user-written critique of mental health services in Toronto area, funded by Ministry of Health —federal

4.0 DISCUSSION OF ISSUES AND IMPLICATIONS

From the wealth of findings some impressions begin to emerge: the Self Help Centre as a fairly well-known and positive presence in the community; services which are clearly beneficial but serving only a small proportion of the self-help/mutual aid constituency; specific concerns about current and past services; self-helpers with an array of wants and needs — primarily having to do with programming — which are not being met by the Self Help Centre. Section 4.2 will show that expectations are growing, probably due to renewed awareness generated by the interview process. In addition to operational, policy and planning implications there are ethical issues to consider.

4.1 Messages from the groups (key relationships in the data)

Having listened to the groups individually, and having seen their summarized responses, what now is their collective voice saying to the Self Help Centre?

About Self-Help/Mutual Aid in Hamilton-Wentworth

Clearly there is an active and growing self help community in Hamilton-Wentworth. Most groups are linked to a sponsoring organization, most are satisfied with how the group is going, and just over half of them are six years old or older -- representing a mature presence in the community. While only about a third of mutual aid groups charge a membership or similar fee, half of them distribute a newsletter. More than half have their own offices and are happy with them, and nearly half of those with offices report additional room facilities.

Nearly half the groups, however, are five years old or younger: evidence that the self help movement continues to grow. Some of the established groups are in a transition time, needing new, younger members with energy to revitalize their work. Nearly a third of all groups are not linked to a sponsoring organization.

Among mutual aid groups, nearly half do not have office space, and most do not charge membership or other fees. More than a quarter of them lack basic office equipment. Sixteen per cent are not satisfied with how the group is going, and some of the satisfied are nonetheless concerned. Some need to establish productive links with the professional health care sector or with other similar groups but lack the resources even to seek out the collaboration they need.

It is among this latter collection of groups that an adequately-staffed Self Help Centre could be of greatest help, by offering low-cost access to skills, resources and information networks that are currently beyond their reach.

About how the Self Help Centre is experienced by self helpers and professional workers

As shown in Section 3.4, the Centre is seen as an important and valuable resource, very much needed by the community. Self helpers are generally more noncommittal than professionals (a third of them responded to the question about "image or impression" with an item of fact rather than a positive or negative comment, while two-thirds of professionals made positive comments) but when asked to rate their satisfaction, 80% of self help respondents said they were satisfied or very satisfied with Self Help Centre services.

On the other hand, about a third of the groups we interviewed had never even heard of the Self Help Centre, a finding consistent across all group types. A few thought they might have read an article in the paper or vaguely knew it existed, but that was all. These people represent a publicity challenge for the Self Help Centre.

The most insightful comments came from people with some experience of the Centre, a sense of its potential, and perhaps some disappointment. A number who were involved at the beginning no longer are; though most didn't say why, there is a noticeable absence of positives and a collective air of let-down when the comments of past users are viewed as a whole. A notable exception came from a professional worker who sees the grassroots nature of self help as being very important and the Self Help Centre as "underutilized" but with "tons of potential". This sentiment is echoed in the evocative metaphor of one respondent who sees the Centre as a Frankenstein with a body made of unmatched parts but no soul, needing spirit to breathe life into it. The same person goes on to say, "However, the concept of self help is the greatest thing we have now."

The overall message is one of widespread support both for the concept of self help and for what has been accomplished so far at the Self Help Centre, but with much more to be done in order for the Centre to be a vital and thriving presence in the community.

About Meeting Space

For the 10% of mutual aid groups who use the Self Help Centre for meetings, it is an important and valued facility; they see it as meeting their needs.

However, most mutual aid groups in Hamilton-Wentworth do not use the Self Help Centre for group meetings. It is the fifth most common choice as a place to meet, and the first four choices combined represent two-thirds of the groups. [See Table 3.1.6] While we did not ask why groups meet where they do, the subject of costs came up fairly often. Churches — for the present, at least — do not usually charge rent; meeting in a member's home would be rent-free; groups meeting at their own office or a sponsoring organization's facility would not be paying extra to have the meetings there.

Annual membership in the Self Help Centre, however -- required in order to use the meeting space 'free' -- costs \$75. Groups who cannot afford that initially -- and several said this was the case -- would be even less able to rent meeting space in the Centre at the minimum of \$10 per hour.

There seems at first to be a discrepancy between needs and wants on the subject of Space: Table 3.4.8 shows that, among Mutual Aid groups, Space is the second most common type of need (20 groups), while it shows as their most common want in Table 3.4.11 (46 groups). The question about needs was very specific to each group, however, (What ... does your group need...?) while the responses we are referring to as "wants" were given in answer to an open-ended question about what the Self Help Centre should offer. Given that most respondents see the Centre as a good thing for the community, it may be that wanting it to offer space for meetings is a way of affirming it as a necessary and valued presence in the community — regardless of whether or not that particular group needs the space. The importance of considering both needs and wants (and the perils of focusing only on one) are set out nicely by Abbey-Livingston and Abbey:

If a decision is made based on a need only, planners run the risk of providing a program that no one wants. If planners offer a program because people want it, that doesn't mean that people will go — they may want it to be available but prefer to attend some other program that is offered at the same time. ¹³ [underlining added]

It is worth noting here that a concurrent Utilization Study was conducted at the Self Help Centre in January-February/96; this study showed that -- in addition to mutual aid groups -- many nonprofit and other community groups also use Centre meeting rooms, on a rental basis. All office tenants at the Centre are nonprofit groups, two of whom have associated self help/mutual aid groups. It also showed that, while meeting rooms are humming three or four evenings a week, there is still lots of potential to develop further the uses of meeting room space. [Copies of the Self Help Centre Utilization Study are available at cost from the Social Planning and Research Council.]

Any future policy or strategic planning decisions about use of Self Help Centre space should be made in the light of both reports.

¹³Diane Abbey-Livingston & David S Abbey, <u>Enjoying Research? A 'How-to' Manual on Needs Assessment</u>. For the Recreation Branch of the Ontario Ministry of Tourism and Recreation, 1982, reprinted by Health and Welfare Canada 1991, p16

About Membership -- Structure, Costs and Benefits

Membership in the Self Help Centre is currently available in three forms: "Full", available to self-help/mutual aid groups only, at \$75 per year; "Associate-Group" at \$40 per year, for other groups or agencies who want to support the Centre; and "Associate-Individual" at \$10 per year, open to anyone.

The main benefit of Full membership is access to meeting room space at very low cost: \$75 per year works out to about \$1.50 per meeting, assuming 50 meetings per year. Not all mutual aid groups meet that often, however, and not all, as we have seen, can pay the full fee all at once. Full members may use the Centre address and retrieve mail from their own mailbox at the Centre; they receive a private voicemail number on the Centre's phone system so that group members can access their voicemail box for messages at any time. They are also offered a "home base for your group", the meaning of which is not clear. Possibly it refers to the combined effect of the foregoing benefits. All of these benefits are associated with the location itself.

Associate Group members receive a 10% discount on meeting room rentals.

Two other benefits are offered to all members: a newsletter, when available, and one vote at the Annual General Meeting. Only two Self Help Centre newsletters have ever been published, in April and May of 1994. The first Annual General Meeting took place in May 1996.

The references above to membership in the Centre, while correct at time of writing due to some hard work by the Self Help Centre Board of Directors during the lifetime of this project, are in historical terms somewhat misleading. The promotional brochure in Appendix B-2 actually offers membership in the Self Help Network, and the other materials also show references to both the Self Help Network and the Self Help Centre. Excerpts from the Network brochure state:

The Self Help Network of Hamilton-Wentworth was formed in 1989. ... After its initial formation, the Self Help Network expanded and sought financial and community support[and] ... in the spring of 1993, the Rotary Club of Hamilton Self Help Centre was born. ... Operated by the Social Planning and Research Council, with volunteer assistance from the Network, the Self Help Centre has become an important meeting place for groups in our community.

It is already clear to the Board of Directors that, in the words of one of them, "the Centre and the Network must become one."

The irony is that the main benefits of Network membership have been attached to the Centre, while the one benefit that is a major aid to networking — the newsletter — is not happening.

About Group Needs and Wants

About 28% of the mutual aid groups picked at least one item from a specific list of possible <u>needs</u>. When asked open-endedly what they <u>wanted</u> from the Self Help Centre, 88% of mutual aid groups wanted at least one thing. Office equipment was the highest category of need; space needs and wants have been discussed earlier in this section.

Everything else the groups want from the Self Help Centre has to do with programming; similar items appear as needs, and as concerns expressed in the context of whether respondents are satisfied with the way groups are going. In essence, groups see the Self Help Centre as their major resource when they need information about self help, want to connect with other groups or have some specific need for help with the group. Wanted services appear as separate items because those were the words the groups chose to use; in fact the actual activities overlap and interconnect in many ways.

Networking tops the list. Many groups are eager to share what they have learned and to learn from the others, and see the Self Help Centre as creating opportunities for this to happen. Some have specific longings for improved relationships with relevant health professionals, and see the Centre as appropriate to facilitate such networking. Electronic networking is also a growing interest, both as a way to be in touch with other groups and as a way to access current information.

Groups want information from the Self Help Centre about community events and what other groups are doing. This could be facilitated in two ways: through electronic networking, as already mentioned, and via a newsletter. Even more vital, access to current research is the mainstay of many self help groups. They are there, often, to keep hope alive for each other, and up-to-date information is a key factor in this process.

Similarly, a well-informed referral service is very much seen as part of Self Help Centre services. Professional workers look to the Self Help Centre as possibly offering a "next step" for their clients, and groups want the professionals to know that they're there. One self help group member spoke of wanting referral to self help groups by professionals to become part of the general health care approach.

Group development activities that groups see the Self Help Centre as offering include help to get a group started, leadership/facilitator training, and workshops or seminars on other topics of interest or concern.

Current topics of concern include member recruitment, volunteer recruitment, and fundraising.

The real implications of all this for self-help/mutual aid groups and the Self Help Centre in Hamilton become much clearer when viewed in relation to what the Centre offers and has currently available. Table 4.1.1 summarizes the items of want, need and concern in relation both to each other and to services of the Self

Help Centre. [Information extracted from Tables 3.4.11, 3.4.12, 3.4.8 - 10 and 3.3.2] By following along a row from left to right, one can see what groups want, need or are concerned about, and then whether the Self Help Centre offers it and/or has it currently available.

It is quickly evident that location-dependent services are meeting highly-ranked wants and needs; on the other hand, only 10% of mutual aid groups are receiving those benefits regularly. Among Outreach Services, there have been two Self Help Fairs, both held at the Centre, the most recent in May 1996. An updated Self Help Directory is planned as a spin-off of this Community Research and Development project, but is in jeopardy due to loss of personnel.

All other items of want, need or concern are not available among current Self Help Centre services. Leaving aside Equipment for the moment, these Outreach services are the very activities that comprise the heart of what most other Self Help Centres have to offer. [See Appendix I: Services Offered by Self Help Centres in Ontario] They are legitimate services for groups to expect from an organization calling itself a "Self Help Centre." The sobering reality is that 90% of the mutual aid groups in Hamilton-Wentworth, according to this survey, are not being served by the Self Help Centre which exists because of them.

Table 4.1.1: WANTS, NEEDS & CONCERNS OF SELF HELP/MUTUAL AID GROUPS COMPARED TO SELF HELP CENTRE SERVICES

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Type of Item	Want From SHC	Needs Beyond current resources	Concerns about group	Membership 'Full' benefits offered	Current SHC Service?
[of 109 Mutual Aid groups]	88% responding	28% responding	20% responding	10% with Full Membership	
Capital items	ı	Equipment	1	1	No
Location-	Space	Meeting space	,	Meeting rooms	Yes
dependent or related services		Answering service / voicemail		Ivialibox Voicemail	
Outreach Services (programming)	Networking (in person & electronic)	Electronic	Relationship with doctors	1	°Z
	Information	Library Resources	Member services Recruitment	Newsletter (when available)	°N
	Group Development	Other programme needs	Group functioning Funding	,	o _N
	Referral Services	t	•	-	No
	Self Help Fair	1	-	1	Yes, at SHC
	Self Help Directory	ı	ŧ	1	coming as
					project spin-off (we hope)
	Publicity	1	ı	1	S.

" -" means no response in this category

About Self Help Centre Relationships with Professionals who lead Support Groups and in Agencies Interest in the Self Help Centre is high among the professional workers we interviewed. They see it as an important and valuable community resource, both as a place to hold meetings and as a demonstration of the community's commitment to grassroots endeavours. Equally important, self help is often seen by them as an appropriate referral for their clients: moving on a continuum from professional help to mutual helping among peers is a way for individuals to exercise independence while still being in -- and helping to create -- a supportive environment. The Centre missed a prime opportunity to assist perspective self-helpers because one respondent who works in the Hamilton General Hospital, directly across the street from the Centre, didn't know it was here, or what it was for: "If I had known a couple of years ago, might have helped start a group for two interested, motivated people; they would have liked Facilitator Training." Self helpers, in turn, need professionals for various purposes: to provide them with technical information or advice; to join them in advocacy efforts to remedy an unsatisfactory situation; to accept referral of a group member who may need professional assistance.

On an inter-agency level, the Self Help Centre can only benefit by sharing interests and challenges with other community agencies, Community Information Service (CIS) being the prime example in the context of this study: a CIS publication was our major way of identifying groups to interview. It is hoped that the Centre can, in return, provide information to CIS that can help make the next such directory even more useful.

The view that self-help/mutual aid groups and professionals can benefit by learning from and developing new relationships with each other is supported by a growing number of authors. In his article, "Professional/Self-Help Group Relationships," Alfred Katz argues very strongly that professionals, in particular, have much to learn from self-helpers, including "experiential knowledge" and "what it is like to be a group member — to participate in the group process, to be respectful of other people's opinions even when you think you know better, and not to attempt to dominate them or the discussion." Vic Constantino and Geoffrey Nelson write about the ability of mutual aid groups to empower people, and how important it is that professionals support this:

The essence of an empowerment approach is that people who have been marginalized gain more control over their lives through active participation in the community (Lord and Hutchison, 1993). Professionals who work from an empowerment approach are respectful and supportive of SHG's and share decision-making power with and provide resources to SHGs [Self Help Groups].¹⁵

¹⁴In Self Help Concepts and Applications, Katz A., Hedrick H., et al, Eds, The Charles Press, 1992, pp 58,59.

¹⁵/_"Changing Relationships Between Self-Help Groups and Mental Health Professionals: Shifting Ideology and Power," in Special Issue: Mutual- Aid Groups and Support Groups, <u>Canadian Journal of Community Mental Health</u>, (14) 5, Fall 1995, p 57.

Later in the same article the authors point out, "At the same time, both professionals and self-helpers stated that education and training is also important for self-helpers, as they can 'learn something from them [professionals]." In the same issue, Andy Farquharson reports on his interviews with ten professionals "who were perceived to exemplify... [a] positive perspective on the value of self-help and mutual aid." Participants offered guidelines for practice based on their contact with self-helpers and reported that, because of such contact, their approach to work had changed. One commented that "(Instead of professionals presuming to train self-helpers) we should reverse the situation and get self-helpers to run workshops for professionals." 17

Returning once more to Alfred Katz, he closes his discussion with the following admonition:

Above all I believe we must recognize that there is no simple blueprint or pattern for the ways professionals and self-helpers can relate to one another and cooperate in helping individuals, families and communities. Flexibility, pluralism, mutual respect, openness on both sides, and trying out new things are the keys to success.¹⁸

The place to begin is where <u>this</u> Self Help Centre finds itself in relation to <u>these</u> groups and <u>these</u> professionals: that is, with our own lived experience, true to the founding spirit of self-help/mutual aid.

About Staffing at the Self Help Centre

The Self Help Centre, as noted earlier, came into being as a project of the Social Planning and Research Council of Hamilton-Wentworth. SPRC staff supervise projects, assist with board development, and oversee building operations and accounts. An outline of past Self Help Centre projects and staffing is presented in Figure 4.1.1: Self Help Centre Timeline. Volunteers — high school or summer placement students or individuals from the community -- assist with building maintenance, reception, room bookings and security. None of these things addresses the networking, group development, information and referral services wanted by groups in any substantial way, although some referrals do follow from work at the reception desk.

The only two newsletters ever issued by the Self Help Centre were produced near the end of its first year of operation, a year during which it had four full-time staff members supported by Human Resources Development Canada. Seventeen months later, HRDC once again supported two staff for the Centre, this time to conduct the study which is the subject of this report. In between, there was no staff at all to do outreach or offer group development assistance; the same is true again as this project comes to an end. Outreach was a deliberate part of each interview, but information or group development services beyond that

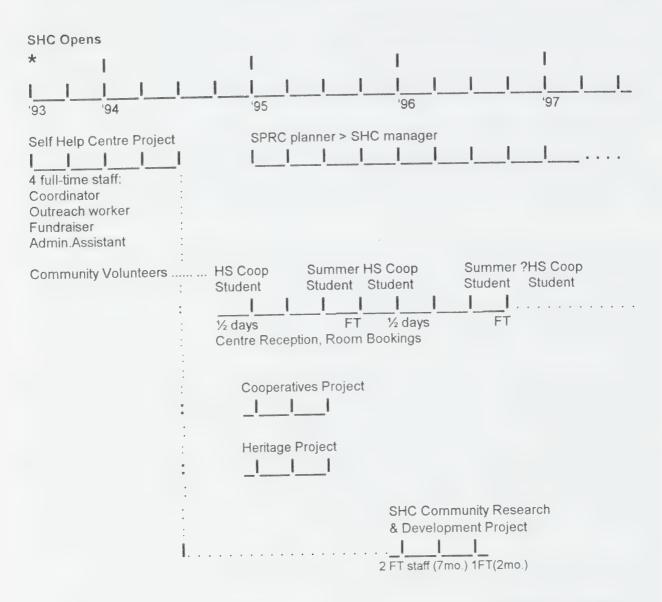
¹⁶lbid, p 63.

¹⁷"Developing a Self-Help Perspective: conversations with Professionals," Ibid, p 86.

¹⁸Op cit., p60

were not explicitly offered. Nonetheless, they began to be expected, as section 4.2 will show.

Figure 4.1.1: Self Help Centre Timeline



Self Help Centre Board of Directors STRATEGIC PLANNING DAY: OCT 5/96

4.2 Growing Expectations of the Self Help Centre

As self-helpers and others in the community became aware that there were now two full-time staff at the Self Help Centre, people began calling the project office for advice and information. Although this was not a direct responsibility of project staff, in the spirit of promoting the Self Help Centre they nonetheless did the best they could to help each caller. Not every call and consultation was recorded because the study design did not anticipate this increased demand, but after a while project staff decided to keep track of such requests. A sample of these minor consultations is shown in Table 4.2.1.

<u>Table 4.2.1: Unsolicited Minor Consultations by Self Help Centre Project Staff, April - August 1996</u>
26 consultations: 20 from Hamilton, 5 from other Ontario cities, 1 from Osaka, Japan

Number	Purpose of Call	Action taken
of Calls 7	Need help to locate a specific group, obtain name of new contact	Referral to current contact person, known to us because of recent survey
6	"Is there a group for?"	Referral to appropriate group, if known; series of calls to various places to track down one possibility
5	Request for general Self-Help information, organizational arrangements.	Referred to other Self Help organizations, contacts, explained local organizations
4	Need help to start a group	Referred to another agency that might be running facilitator training; sold one manual - <u>Towards Effective Self Help</u> ; invited one caller to our Self Help Fair and Annual General Meeting in May/96
1	Help to revive a group "in decay"	Couldn't adequately address this one; referred to another agency's waiting list for Facilitator Training (which was not yet scheduled)
1	Group seeking a place to learn to cook nutritious and economical meals	Referred to local Community Kitchen
1	Group wanting to become members of the Centre	Sent membership information
1	Visiting representative from Osaka Self Help Support Centre, Osaka, Japan	Received request and extended invitation to visit by e-mail via SHC Board Member; showed visitor our facilities, shared information, sold him one copy of our facilitator training manual, promised to send one copy of Community Research & Development Report (with invoice).

These requests for help are consistent with many of the "messages" identified in Section 4.1 above.

During the summer of 1996, a summer placement student staffed the Self Help Centre reception desk and logged messages directed to Self Help Centre reception. At present, the Centre phone is not answered directly, even if someone is there when the phone rings; callers must listen to a recorded greeting and then select the number for Reception, at which point the receptionist can make contact with the caller or the caller is redirected to voicemail. This means that a caller must be determined and persistent to get a message through, and then be prepared to leave a message and wait once more for a reply. Despite this barrier, some callers do persist. Table 4.2.2 shows the number of calls logged over six weeks in the summer and the purposes of the calls.

Table 4.2.2: Voicemail Inquiries to Self Help Centre Reception, June 13 - July 31/96

Number of Calls		Purpose	e of Call	
received in:	Self Help Information	Room Booking	Other SHC Business	All Calls
June (~2 weeks)	9	4	4	17
July (~4 weeks)	9	3	2	14
6-week total	18	7	6	31

Clearly June was a busier time overall, with more calls in 2 weeks than in the whole month of July. What is significant to this discussion is that in each month there were more calls for Self Help Information than for Room Rentals and Other SHC Business combined. Once again, this supports the findings of the survey that groups want information services as well as use of meeting rooms.

In both the above cases -- minor consultations by project staff and calls to the Reception Desk -- incoming requests were spontaneously generated from the community. No public announcement alerted them to increased capacity for response at the Centre. As word spread, however, the expectations created by the very visible presence of the Self Help Centre could be expressed with reasonable assurance that there would be an informed response. These unsolicited inquiries are clear evidence that the community expects to obtain information and assistance regarding self help from the Self Help Centre; if the capacity for such assistance were publicized, the response would very likely be much greater, and more of the community's needs would be met.

Taken together, these expectations and the formal findings of this study send a very strong message: the community is looking for informed and responsive services regarding self help, and they expect the Self Help Centre to provide them!

4.3 Ethical Issues to be Considered

Section 2.2 of this report discussed the methodological importance of sorting out which groups were truly self-help/mutual aid and which were not. For the Self Help Centre, this is also an ethical issue callers seeking self help assistance expect — and rightfully so — clear, well-informed answers. Although many self-helpers have strong and beneficial working relationships with professional workers, a substantial number do not. Many self-helpers have a strong resistance, based on past experience, to any professional involvement whatsoever with the group; some callers are very explicit when asking for "a group for (x) that is not led by a professional." Such people must be honoured in their need, and that requires an ethical commitment from those answering their inquiries to know the nature and leadership characteristics of the groups they might suggest. More than once during the survey we could not tell from the directory description of a group whether there was a mutual aid component or not; therefore, we would not have been able to offer clear information about those groups to a caller. Only in the interview were we able sometimes to learn enough that we could confidently describe such a group in terms of its mutual aid component (or alternative services). Even so, we are still left with some questions which we would hope to answer before, say, producing a new directory.

The second ethical issue for the Self Help Centre arises from the 'promise' contained in the Network mission statement, the purpose of the Self Help Centre and the goals and objectives subsequently adopted by the Self Help Centre Board of Directors. Taken together, these describe the mandate of this organization, and the ethical dilemma lies in the gap between the Centre's mandate and the services it is actually offering. This report has shown that current services are focused almost exclusively on the physical facility, but these relate to only one of the five goals set by the Board in the summer of 1995 [Goal #3, see Appendix A]. The other four have to do with self help promotion and outreach; while some of the associated objectives are being addressed, more are not, and there simply is not the capacity right now to meet them.

The serious question before the Board is: What must be done to achieve these goals, and what would be the consequences if they are not met? No one wants to fall short of a promise, but good intentions must be supported by vigorous and sustained action in order to fulfill the mandate. There is particular urgency to this question because March 1998 is fast approaching, when the Self Help Centre anticipates becoming independent and no longer a project of the Social Planning and Research Council.

5.0 ACTION RECOMMENDATIONS TO THE SELF HELP CENTRE BOARD OF DIRECTORS

Much has been accomplished at the Self Help Centre in the three years since it opened. As a physical facility, it is unique in the self-help field, and it clearly is valued in the community. Similarly, considerable thought and care have gone into such things as defining goals and objectives, characteristics of self help groups, and policies and procedures for the Centre. The following recommendations are offered in full recognition of the important groundwork that has already been done, in hopes of assisting the Board to clarify next steps toward fulfilling their mandate. No attempt has been made to specify particular operational, policy or strategic planning implications, in the belief that the Board is entirely capable of identifying and dealing with these as they become evident in consideration and discussion of the recommendations.

Recommendation 1:

Continue to strive to clarify the functions and philosophy of the "Network" and the "Centre" until they work effectively as a unit" At minimum this would include attention to the mission statement, goals & objectives, and policies and procedures but should be limited only by the scope of the mandate.

Recommendation 2:

Continue to support self help/mutual aid priority of sufficient meeting space as supported by data in this and other studies.

Recommendation 3:

Recognize the importance of planning for an orderly transfer of building operations and management from the Social Planning and Research Council to the Self Help Centre.

Recommendation 4:

Assess the need for renovations and capital expenditures in order to enhance the meeting and conference services of the Centre and create better opportunities to generate revenue; plan and initiate a capital fundraising campaign to cover these costs. This assessment should begin with specific comments offered by respondents in this study, and include such things as kitchen renovations, auditorium renovations, small storage for member groups, and presentation equipment such as overhead projectors, flipcharts, sound system, etc, for use in meetings.

Recommendation 5:

Develop one room in the Self Help Centre to be the "nerve centre" for support services to the self help/mutual aid movement in Hamilton-Wentworth. This could include: Self Help Centre administration and records; staff work space; computers and other office equipment for use of self-helpers; library resources. An open, welcoming, "drop-in" atmosphere could offer the sense of "home base" that seems to be vague or missing in what is currently being offered.

Recommendation 6:

To maintain continuity of service at the basic level of information and referral and "bare-bones" self help support that is personal, informed, accessible and friendly. In particular, it should be possible for callers to be answered directly by a live human being, when available, and for that person to leave a personable, easy-to-update message when she/he needs to be away from the phone.

Recommendation 7:

Fulfill the Centre's mandate by offering program services in accordance with its goals and the expectations of the self help community. These services should include but not be limited to: facilitator training and other topical workshops; help with group start-up and revitalization; help to access resources such as computer networks, written and other media resources, and relevant professionals or other helpful persons.

Recommendation 8:

Begin outreach to self help/mutual aid community by focusing on 1) groups that expressed specific concerns or problems in the survey and 2) groups within a certain focus that seemed more "needy" than others, i.e. groups with a focus on Employment, Social Advocacy, Disability, Abuse, Ethnocultural, Workplace Safety and Seniors issues; then widen to include the broader self help community.

Recommendation 9:

Restructure costs and benefits of membership in the Self Help Centre to 1) make it more affordable to those for whom it is currently beyond their financial means; 2) more closely align costs and benefits with self help community needs and the Centre's mandate; 3) make membership more widely beneficial and thereby attract more members. One example of how this might be done is offered for consideration in Appendix K.

Recommendation 10:

Recognize that supports for individuals exist on a continuum -- from individual therapy or counselling by a professional, to support groups led by professionals, to self-help/mutual aid groups, to the general community support offered by caring friends and neighbours, to the intimate support of a loving family -- and that each type of support is appropriate for certain circumstances, and all should be welcomed and encouraged for their legitimate place in the continuum.

Recommendation 11: Build on existing good will toward the Self Help Centre by forging stronger, more collaborative and dynamic relationships with community and professional agencies and leaders of support groups, based on discussion earlier in this report.

•	

6.0 FURTHER RESEARCH QUESTIONS FOR ANOTHER PROJECT AND ANOTHER TIME

Much has been learned in this study, and -- as with any such project -- more questions arose than we could answer as we went along. Some have already been noted in the body of the report; one or two are, perhaps, more subtle. Each of the questions listed below could have significance for policy and planning decisions at the Centre; it will be up to future researchers and planners to decide on priorities -- or find new questions.

Question 1: Do the groups meet regularly? How often and When?

This information is available on disk, in the project database, for future analysis if desired.

Question 2: For groups with newsletters, how often are they sent out?

Again, this is available on disk in the project database. Additional questions (for which we have no existing data) that may be of interest on this question are: Where is the newsletter produced? Who edits, who writes it? How much time is spent in producing each issue? How large is it? What is the circulation? What does it cost to produce? To mail? How are the costs of production paid for?

Question 3: Where are the groups located?

This question is not as straightforward as it looks. Where the groups have their offices (for those that do) may be where they meet, but not necessarily. Most groups have a mailing address, and we do have postal codes in the project database, but some groups are intentionally available only by phone. In many cases, an executive member or leader who keeps the files at home -- and provides the temporary mailing address - , and this may change as roles change. Although it seemed most of the groups we interviewed were in Hamilton-Wentworth, we also travelled to Caledonia and Grimsby and have received calls from St Catharines, so the question may be come more important in the future.

Question 4: When a group identifies a need for Space, does it necessarily follow that the Self Help Centre can fill it?

This is another place where the question of location becomes important, along with other questions about particular facilities. Some groups, because of the geographic distribution of their members, prefer to meet "close to home," and that may not be near the Centre. Others may need particular storage facilities which the Centre does not provide. Issues of anonymity and confidentiality are extremely important and delicate in some cases: the prospect of having to walk through a public space to reach a meeting room is a significant challenge for some, and the problem may not be solved even once the person arrives at the meeting room. One group at least has raised concerns about sound "leaking" from one of the Centre's meeting rooms to the next. It would be useful to monitor such questions further, in order to plan appropriately.

Question 5: What are the economic benefits of self-help/mutual aid?

In an economic climate of severe fiscal constraint, this question may become critical. Can people in crisis return to work sooner when they are supported by a mutual aid group? How much money does "fewer days of work lost" save the employer? How much more tax revenue does an earlier return to work generate? How many would have been hospitalized if they hadn't had a mutual aid group? What would the costs of hospitalization have been? What is the financial impact on the individual household of a member who is more productive because of the support of a mutual aid group? What is the impact on the local economy? These questions only begin to sketch the possibilities.

This list is not exhaustive, of course. The questions are those which became obvious during the course of the project, and are offered for the benefit of those who will carry on from here. No doubt the future will bring its own questions to add to the mix.



THE SELF HELP CENTRE OF HAMILTON-WENTWORTH BOARD OF DIRECTORS

GOALS FOR THE NEXT TWO TO THREE YEARS.

The following goals are not listed in any order of priority. These goals may still evolve over time.

1. To increase the awareness of the principles and practice of self help in the Hamilton-Wentworth community.

<u>Objectives include</u>: inform and educate community residents, professionals and other service providers about the Self Help Network; develop linkages with community organizations in Hamilton-Wentworth; promote self help public relations opportunities.

2. To sustain the viability of the Self Help Network through maximum participation from self help groups in the Region.

<u>Objectives include</u>: pursue and achieve incorporation and charitable status; increase the number of members in the Network; nurture the well-being of self help groups; achieve and sustain full Board membership.

3. To facilitate and strengthen the viability of the Self Help Centre as a resource for self help groups and the wider Hamilton-Wentworth community.

Objectives include: secure financial resources to support core staff infrastructure to provide coordination and planning, security and maintenance; develop and sustain a volunteer program to support the Centre; secure and maintain maximum office space rental capacity; secure and maintain maximum room rental capacity for self help groups; develop policies and procedures for staff and volunteers of the Self help Centre.

4. To facilitate the growth and development of self help groups in the Hamilton-Wentworth Region through the provision of developmental support and sharing of technical resources.

Objectives include: develop and sustain Self Help Centre infrastructure to support developing self help groups (e.g., voice mail, etc.); develop and sustain support tools (e.g., facilitator training, etc.); provide opportunities for interactive forums for self help groups to link and learn from one another and share skills; develop an information and referral service.

5. To educate other groups in Canada about the unique development experience of the Self Help Network and the Self Help Centre.



APPENDIX B-1

Questionnaire: "First Visit Record"

3-1-

SELF HELP CENTRE / SELF HELP NETWORK

OF HAMILTON-WENTWORTH

FIRST VISIT RECORD

As in Directory / S		oup
	2. Which best describes your g .1□ PEER LED, no profes	ofessional involvement
	.3□ mutual support, F	PROFESSIONAL-LED
	.4□ transitioning [from	to:1
	.6□ Other (specify)	
	3. Name of CONTACT PERSO	DN
	4. MAILING ADDRESS of orga	anization
	5. TELEPHONE NUMBER (Type of contact:)
		.3□ home line of contact person .4□ work line of contact person .6□ other
	6. FAX NUMBER ()
	7. e-mail address	

8. W	hat are the OBJECTIVES of your organization?
9. W	hat are the ACTIVITIES / SERVICES of your organization? [includes educational
mee	tings, telephone support]
	Membership Information
How Ion	g has your group been in existence?
low lon	g has your group been in existence? less than 1 year
low lon	g has your group been in existence?
low lon	g has your group been in existence? less than 1 year 1 - 5 years
.1 .2 .2	g has your group been in existence? less than 1 year 1 - 5 years
.1 .23	less than 1 year 1 - 5 years 6 - 10 years
.1	less than 1 year 1 - 5 years 6 - 10 years more than 10 years
.1	less than 1 year 1 - 5 years 6 - 10 years more than 10 years Don't know
.1	less than 1 year 1 - 5 years 6 - 10 years more than 10 years Don't know by members in your group? 2 - 5
.1	less than 1 year 1 - 5 years 6 - 10 years more than 10 years Don't know y members in your group? 2 - 5 6 - 10
.1	g has your group been in existence? less than 1 year 1 - 5 years 6 - 10 years more than 10 years Don't know y members in your group? 2 - 5 6 - 10 11 - 20
.1	less than 1 year 1 - 5 years 6 - 10 years more than 10 years Don't know y members in your group? 2 - 5 6 - 10

13.	How ofter	n are meetings held?	
	.1□	daily	
	.2□	weekly [which day?]	_
	.3□	biweekly or twice a month [which days?]	
	.4□	monthly [which day?]	
	.5□	as needed [when, usually?]	
	.6□	Other	_
14.	Where d	oes the group meet? [check all that apply]	
	.01□	member's home	
	.02□	SH group office	
	.03□	sponsoring organization's facility	
	.04□	Self Help Centre	
	.05□	church	
	.06□	community centre	
	.07□	public library	
	.66□	other	
	.77□	Refused	
	.99□	Not applicable	
15.	Are your	self-help meetings open1 To the general public □Yes □ No □ N/A	
		.2 To members only ☐ Yes ☐ No ☐ N/A	
		.3 To prospective members ☐ Yes ☐ No ☐ N/A	
		.6 Other [researchers,etc.]	
		.7 Refused	
		.8 Don't know	
		.9 Not applicable	
16.	How does	s one become a member?[self-referral, professional referral, etc.]	
			_
17.	Is there a	membership fee? ☐ No ☐ Yes	
18.	[If yes to	17] What is the membership fee?	

Res	sources
19.	Does your SH group have an OFFICE? ☐ Yes ☐ No [go to 24]
20.	[if Yes to 19:] Where is it located?
	STREET ADDRESS of organization
	Poetal Code:
Alac	Postal Code:
Nea	arest main Intersection:
21	What FACILITIES do you have in your office?
22.	Are you satisfied with your office? □No □Yes [go to 24]
23.	[If No to 22:] Why not?
	What INFORMATION resources does your group have? (eg. movies, lending library, pamphlets,
cas	ssettes, etc.)
25	Do you have a NEWSLETTER?□ Yes □ No [go to 28]
20.	bo you have a Newsell Filt. In for the figure 199
26.	[If yes to 25:] How often printed? .1 weekly
	.2□ monthly
	.3□ quarterly
	.6 other
27.	Can we receive a copy? ☐ Yes ☐ No

Enl	nanced Access to	o your Activities/Services [chec	ck all that apply]	
28.	Do you offer:	.01Transportation	□ Yes □ No □ n/a	
		.02 Hearing devices (TDD)	□ Yes □ No □ n/a	
		.03 Child Care	□ Yes □ No □ n/a	
		.04 Braille elevator	□ Yes □ No □ n/a	
		.05 Wheelchair access	□ Yes □ No □ n/a	
		.06 Sign language interpreter	□ Yes □ No □ n/a	
		.07 Cultural interpreter	□ Yes □ No □ n/a	
		.08 e-mail	☐ Yes ☐ No ☐ n/a	
		.09 24-hour emergency pager	r □ Yes □ No □ n/a	
		.66 Other		
29.	Do you have pro	visions for nonsmokers?		
Sat	isfaction with Sh	l Group		
30.	Are you satisfied	with the way your group is functi	ioning right now?□ No □ Yes	go to 32]
31.	[If No to 30:] W	hat are your concerns? [eg. group	p communication, morale, proble	n-solving, etc.]
-				-
				res
	isfaction with SH			
32.	. Do you know about the Self Help Centre? ☐ Yes☐ No[go to 42]			
33.	What are your in	npressions/what is your image of	the Centre?	
	11		Ah a Calf Hala Cartago	
34.		ever used the services offered at	the Self Help Centre?	
	□Yes □ No		10 (
35.	[If Yes to 34:] \	Which services have you used in t	the past? (meeting rooms, etc.)	
36.	Does your group	currently use the services of the	Self Help Centre? □Yes □ No	go to 40]
			rrently use?	
07.	in too to con, it	non control deco year great		
38.	Are the services	of the Self Help Centre meeting y	your needs? □No □Not Sure	□Yes [to 40]
39.	[If No or Not Sur	re to 38:] Please explain why not		

	Bot coni	ces/facilities does your group need beyo	nd wha	t you ha	ive now?	
0. V	viiat servi	ooditaciintico acces je an great in the				
	.01	FAX machine	□Yes	□No	□Not Sure	
	.02	photocopier	□Yes	□No	□Not Sure	
	.03	answering service/voice mail	□Yes	□No	□Not Sure	
	.04	computer for typing, data management	□Yes	□No	□Not Sure	
	.05	computer networking	□Yes	□No	□Not Sure	
	.06	place to hold SH meetings	□Yes	□No	□Not Sure	
	.07	place to hold fundraising events	□Yes	□No	□Not Sure	
	.08	library of SH manuals, reports etc.	□Yes	□No	□Not Sure	
	.66□	Other				alarene
	.99□	Not applicable, have enough				
1. C	n a scale	of 1 to 5, please indicate how satisfied	you are	with the	e services of t	the Self Help
					find)	
Centre	e: (please	e circle one number, 5 = very satisfied,	1= very	dissatis	neu)	
Centre	e: (please		1= very	dissatis I	lied)	
V	I1 ery dissatisf	e circle one number; 5 = very satisfied,		4	very	5 satisfied I Fair]
v 12. \	1 1 ery dissatisf What (if a	e circle one number; 5 = very satisfied, 2	tre to of	4 fer? [wo	very orkshops, SH	satisfied
v.	1 1 ery dissatisf What (if a	e circle one number; 5 = very satisfied, L 2 3 fied nything) would you like the Network/Cen	tre to of	4 fer? [wo	very orkshops, SH	satisfied
v. 42. \ 43. □	l1 1 ery dissatisf What (if a) O you kno	e circle one number; 5 = very satisfied, L 2 3 fied nything) would you like the Network/Cen	tre to of	4 fer? [wo	very orkshops, Sh e Self Help?	satisfied
v: 12. \	l1 1 ery dissatisf What (if a) O you kno	e circle one number; 5 = very satisfied, I 2 3 fied nything) would you like the Network/Cen ow we have a Self Help Manual called I	tre to of	4 fer? [wo	very orkshops, Sh e Self Help?	satisfied
v. 12. \ 13. D	l1 ery dissatisf What (if a) o you know □Yes Oo you know □No	e circle one number; 5 = very satisfied, I 2 3 fied nything) would you like the Network/Cen ow we have a Self Help Manual called I No ow of any new groups that might like to	tre to of owards	4 fer? [wo	very orkshops, SH e Self Help? Self Help Cer	satisfied
v. 12. 1 13. D 14. D	l1 1 ery dissatisf What (if a) Oo you knoYes Oo you knoNo No No	e circle one number; 5 = very satisfied, L 2 3 Tied The satisfied of th	owards hear above Network	4 fer? [woo	very orkshops, Sh e Self Help? Self Help Cer e?	satisfied
v. 12. 1 13. D 14. D	l1 1 ery dissatisf What (if a) Oo you knoYes Oo you knoNo No No	e circle one number; 5 = very satisfied, I	owards hear above Network	4 fer? [woo	very orkshops, Sh e Self Help? Self Help Cer e?	satisfied

APPENDIX B-2

Self Help Centre Promotional Package

Self Help Network of Hamilton-Wentworth

WE EXIST BECAUSE OF YOU

We are your networking and education CENTRE: able to provide your group with an address, mail box, phone mail, meeting place, and more!!!

What is the SPRC?

The Social Planning and Research Council is a non-profit, registered charitable organization. They are governed by a community-based Board of Directors and carry out their daily work through full-time staff, special project staff and placement students.

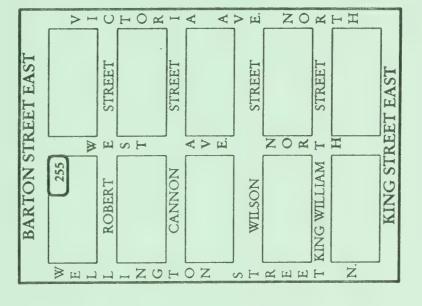
The SPRC is mandated to assist a wide variety of community groups and organizations in Hamilton-Wentworth. The following groups receive our services:

 Non-profit organizations within the Region community groups, neighbourhood associations and special interest groups

 City, Regional, Provincial and Federal Governments.

within the Region.

The Self Help Network is located at 255 West Avenue North Hamilton, ON L8L 5C8 Parking is available next to the building



Pamphlet issued November 1995

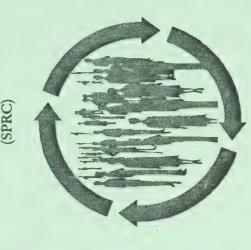
Discover how the

SELF REELP NETWORK

of Hamilton-Wentworth

can help you!!!

A project of the Social Planning and Research Council of Hamilton-Wentworth



TELEPHONE: 905-522-7353 ext. 0 FAX: 905-522-9374 TDD: 905-522-0434

OUR MISSION

To provide support, resources and to foster the growth and development of Self-Help support groups.

What is the Self Help Network?

The Self Help Network of Hamilton-Wentworth was formed in 1989. The purpose of the Network is to encourage the self help movement in Hamilton by offering groups a chance to share knowledge and resources.

After its initial formation, the Self Help Network expanded and sought financial and community support. With a substantial grant from the Rotary Club of Hamilton, the old West Avenue School was transformed into offices and meeting space for the Network, other community groups, and the Social Planning and Research Council, our main supporter and financial trustee. That is how, in the spring of 1993, the "Rotary Club of Hamilton Self Help Centre" was born.

The purpose of the Self Help Centre is to provide a networking facility for members of the Self Help Network. Here groups can meet, share information, and hold special events. Operated by the Social Planning and Research Council, with volunteer assistance from the Network, the Self Help Centre has become an important meeting place for groups in our community.

Anyone who is interested in serving on the Network Board of Directors should give us a call at 522-7353 ext. 0.

Help us help others by becoming a member of the SELF HELP NETWORK

Memberships:

1. Full Membership ... \$75 annually (Self-Help Groups Only)

You Receive:

- A "home base" for your group.
- A mailing address.
- Telephone voicemail box.
- A newsletter. (When available)
- Private meeting space on a cooperative basis.

(Based on one room per booking only)

One vote at the Annual General meeting.

2. Associate Memberships

A group, organization or individual who supports the Self-Help concept.

A. Group/Organization... \$40 annually

You Receive:

- 10% discount on meeting space rentals.
 (Based on one room per booking only)
- A Newsletter. (When available)
- One vote at the Annual General meeting.

B. Individual... \$10 annually

You Receive

- One vote at the Annual General meeting.
- A Newsletter (When available)

For a membership application form, please call: 905-522-7353 ext. 0

Prices and services are subject to change without prior notice.

RESOURCES AVAILABLE:

A LIBRARY

of resource materials is being developed. Contributions of self help books, videotapes and cassette tapes are appreciated.

MEETING ROOM RENTAL

Board Room	Room 6	Room 1	Room 4b	Room 4a
up to 30	up to 30	up to 20	up to 15	up to 10 people \$10/hr
\$15/hr	\$15/hr	\$10/hr	\$10/hr	le \$10/hr

Auditorium up to 100 people \$60/initial 4hrs & \$10/each additional hour.

A SELF HELP TRAINING MANUAL: Towards Effective Self-Help

This manual is a guide for anyone involved in a Self-Help group: members, facilitators, or professionals working with self-helpers. Its main focus is on sensitive and effective leadership and facilitation skills - the "how to" of organizing and running groups. Set up as a series of ten training sessions, it can also be used more informally as a resource book for workshops or for activities for individual Self-Help group members.

\$20.00 plus \$5 shipping and handling.

FABULOUS FEBRUARY

DNE COUPON PER INTERVIEW

SELF HELP CENTRE FREE SPACE PROMOTION 1995 February

SPECIAL
OFFER
from the
SELF
HELP
NETWORK



for first-time users only:

FREE FIRSTS in FEBRUARY

To book FREE meeting space all month CALL 522-7353

Bring your group to the Self Help Centre for your regular February meetings -- on us! Have a look at the place, tell us how to make it better. Complete this coupon, leave it in the Bookings Book when you come for your meeting, and we'll call it even!

Meeting Date: _	/_	/_		
	уу	m m	dd	
Group name:				
Contact person:				
Phone				

Subject to availability. Some conditions apply -- call us to find out what we have to offer!

SPECIAL
OFFER
from the
SELF
HELP
NETWORK



for first-time users only:

FREE FIRSTS in FEBRUARU

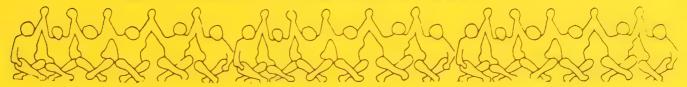
To book FREE meeting space all month CALL 522-7353

Bring your group to the Self Help Centre for your regular February meetings -- on us! Have a look at the place, tell us how to make it better. Complete this coupon, leave it in the Bookings Book when you come for your meeting, and we'll call it even!

Meeting Date: _	/_	/		
	у у	m m	d d	
Group name:				
Contact person:				
Phone				

Subject to availability. Some conditions apply -- call us to find out what we have to offer!

SELF HELP CENTRE AND SELF HELP NETWORK OF HAMILTON-WENTWORTH



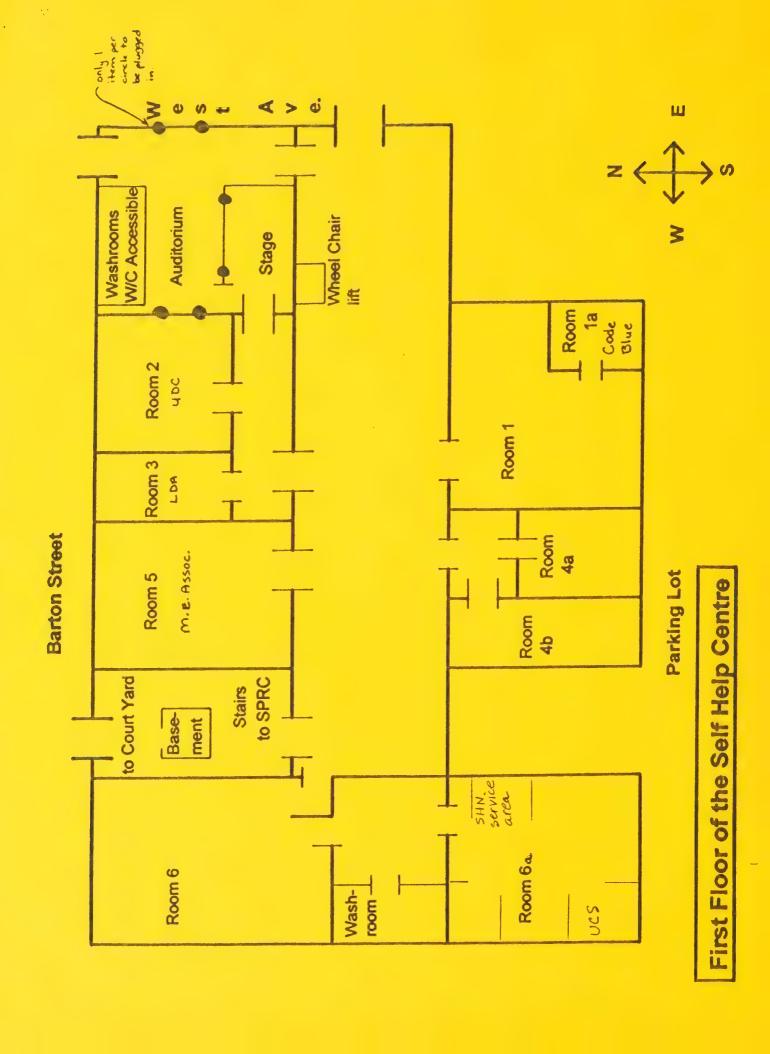
Come and discover a world full of alternatives, care and friendship. We exist because of you, so come and visit us at the Self Help Centre.

We offer:

- * Information about more than 150 Self Help Groups in Hamilton-Wentworth.
- * A group facilitation training manual for those interested in starting a new Self Help Group and for those interested in keeping existing groups alive and well.
- * Meeting Rooms and an Auditorium for your group's meetings and events.
- * A place to meet others and to connect with other Self Help Groups from the community.
- * Information on events and activities of Self Help Groups in the community and much more.
- * Information on how to become a member of the Self Help Network of Hamilton-Wentworth, which includes access to telephone voicemail, private meeting space, use of the auditorium, a permanent mailing address, access to a fax machine, and many other resources with LITTLE OR NO ADDITIONAL COST!!
- * A free parking lot is available beside the building; or take the bus -- it will leave you just a few steps from the Centre.

The Centre is located at: 255 West Avenue North (corner of Barton Street, across from the General Hospital). If you need more information, please call us at (905) 522-1148 ext. 319 and ask for Ronaldo or Caroline. We will be happy to hear from you!!

^{*}Prepared by Ronaldo Parada, SHC Community Development Worker, Dec./95.



SELF HELP NETWORK of HAMILTON and DISTRICT

MISSION: To provide support, resources and to foster the growth and development of self-help support groups

MEMBERSHIP

1. Full Membership (Self-Help groups only) ... \$75 annually

A self-help group whose primary purpose is to empower themselves as individuals and each other to deal with a challenging or unusual or difficult life circumstance. The group is made up of two or more individuals and are not facilitated by a professional.

You Receive

- A "home base" for your group.
- A mailing address.
- Telephone voicemail box.
- A newsletter. (When available)
- Private meeting space on a co-operative basis. (Based on one room per booking only)
- One vote at the Annual General Meeting.

2. Associate Memberships

An organization, group or individual who supports the self-help concept and the future of the Self Help Network and the Self Help Centre.

A. Organization / Group... \$40 annually

You Receive

- 10% discount on room rentals. (Based on one room per booking only)
- A newsletter. (When available)
- One vote at the Annual General Meeting.

B. Individual... \$10 annually

You Receive

- One vote at the annual general meeting.
- A Newsletter. (When available)

APPLICATION for MEMBERSHIP

API	PLICATION for MEMBERSHIP
Name of Group:	Date:
Contact Name:	Phone Number:
Address:	
Type of membership: 1. Full []	2. Associate - Group [*] or Individual []
How often do you meet and when:	
Number of members:	We would like a voicemail box: [] Yes [] No
The Network needs your help to survi	veWe would like to volunteer: [] Yes [] No

TDD: (905) 522-0434



THE SELF HELP CENTRE PRICE LIST FOR MEETING ROOM RENTAL

(There is no room rental charge for members of the Self Help Network)

Room 4Aup to 10 people	\$10.00/hr.
Room 4Bup to 15 people	\$10.00/hr.
Room 1up to 20 people	\$10.00/hr.
Room 6 up to 25 people	\$15.00/hr.
Board Roomup to 30 people	\$15.00/hr.
Auditoriumup to 100 people\$60.00)/minimum 4 hrs.

Please note: there is no minimum charge for small groups that need to rent a wheelchair accessible meeting space, ie: the auditorium. It will be available for a cost of \$10.00/hr.

The above rates are applicable only to weekdays and evenings, Monday to Thursday. Allow time for set up and clean up. There is an extra security fee for Friday nights and weekend rentals.

Commissionaire (if available).....\$10.00/hr.

GST will be added to the Security cost, if the Commissionaire is not available.

All fees payable TWO WEEKS in advance.

The Self Help Centre must have 24 hours notice for cancellations or amendments to the booking. If notice is not received, the group will be invoiced for the time booked even if the room is unused. When groups leave early they will be invoiced for the time they booked, not the time spent in the room. Groups running longer than their scheduled time will be invoiced for the additional time. (When booking a room, please include set up time).

The set up and clean up, of all rooms, are the responsibility of the group renting the room. Groups may be billed if the room is not returned to its original condition.

Only light refreshments may be served (finger foods, veggie trays, coffee, tea & juice). All coffee supplies are the responsibility of the person, group or organization renting our facilities. A 50 cup coffee urn is available to be booked for your use.

The Centre is a smoke free environment.

All groups must provide their own equipment, e.g. overhead projectors, flip charts, etc.

The following things are not permitted in the centre: excessive noise, music, alcohol, chemicals, paints, and any material that might damage the centre.

No pets allowed, except for those who assist people with disabilities.

For more information and / or Booking: Call the Self Help Centre at 522-7353.

The Social Planning and Research Council of Hamilton-Wentworth and the Self Help Network of Hamilton and District are not responsible for any lost or stolen items while on the Rotary Club of Hamilton Self Help property.

Updated July 6, 1995

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Now Available through the Self Help Network:

A Self Help Training Manual: Towards Effective Self-Help

This manual is a guide for anyone involved in a self help group: members, facilitators, or a professional working with self-helpers. Its main focus is on sensitive and effective leadership and facilitation skills - the "how to" of organizing and running groups. Set up as a series of ten training sessions, it can also be used more informally as a resource book for workshops or for activities for individual self-help group members.

Cost: \$25 per copy, (includes Shipping and handling)
o order a copy fill out this form:
would like to order copy(ies) of Towards Effective Self Help.
roup Name:
ontact Name:
ldress:
one Number:
nd with a Cheque, made out to:
The Self Help Network
255 West Avenue, North
Hamilton, ON L8L 5C8
Call 522-7353 ext. 0

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CHARACTERISTICS OF SELF HELP GROUPS AS DEFINED BY THE SELF HELP CENTRE OF HAMILTON-WENTWORTH BOARD OF DIRECTORS

May 1996

The following list of self help/mutual aid characteristics was adapted from the International Network for Mutual Help Centres. These characteristics are used by the Self Help Centre Board of Directors as it makes decisions about a) groups which request full membership in the Self Help Network, b) potential new tenants in the Self Help Centre as well as c) those who wish to use meeting rooms at the Centre.

- 1. Self help or mutual aid is a process wherein people who share common experiences, situations or problems can offer each other a unique perspective that is not available from those who have not shared these experiences.
- 2. Self help groups are run by and for group members. Professional providers may participate in the self help process at the request and sanction of the group and remain in an ancillary, or consultant role.
- 3. Activities focus on mutual support through discussion and sharing of information and experiences, but may extend to other activities and ways of interacting.
- 4. Self help groups are open to members of the general public who share a common experience.
- 5. Self help groups stay in contact on an ongoing basis. Groups are voluntary, and open to new members.
- 6. All self help groups are non-profit. In most cases, there is no charge to participate in a self help group, although a nominal donation to cover the group's expenses is sometimes requested but not required.
- 7. Self help groups may train peers who can then go on to support the group as it evolves.
- 8. Self help groups may engage in advocacy, but any advocacy activities are a direct result of group members' shared life challenges.

These are intended to be used as basic guidelines within the context of the Board's mission statement, the Ontario Human Rights Code and the Canadian Charter of Rights and Freedoms. If a group is not happy with a decision made by the Board of Directors and there is clarifying information which may affect the decision, a group may appeal the decision back to the Board of Directors.

Appendix D

Self Help Centre Community Research and Development Project

GROUP MEETING OBJECTIVES

One of the mechanisms to be used in order to provide with information and at the same time collect data from the variety of self help groups in the area would be a personal meeting.

According to others' experiences (Clearinghouse in Toronto), this is the most effective way to build up a good relationship with the groups and to open lines of communication in permanent basis.

Our basic objectives are:

- Explain the project: Self Help Centre, resources, uses, importance, etc. and encourage the group's participation in shaping it.
- Inform the groups about the Self Help Network.
- Encourage the different groups to take membership and present a list of the benefits of membership.
- Present the groups with the manual for group facilitators and encourage them to use it.
- Ask about special expertise the group would be able to share with others.
- Ask the groups their expectations regarding the SHC. What they would like to see happening. What services and/or types of support they would like us to offer. Assistance, referrals, group development, workshops, etc.
- Encourage the groups to maintain permanent contact with the SHC and the SHN.
- Identify and document groups in existence, who they are, for how long have they been in existence, etc.

^{*}Prepared by Ronaldo Parada, Community Development Worker, Dec./95.

Appendix E

ALPHABETICAL LIST OF GROUPS SURVEYED:

Agoraphobia Group
Air Force Asthma Program
Alanon/Alateen
Alcoholics Anonymous
Alternate Care Program
Alternatives For Youth
Alzheimers Society
Amyotrophic Lateral Sclerosis Society
Anorexia Bulimia Support Group
Arborcare Bereavement Support Group
Arthritic Club

Beginnings Counselling and Adoption Services
Bereaved Families of Ontario
Bereavement Services, Support and Education
Borderline Psychotherapy Support Group
Brainy Bunch Support Group
Bridge from Prison to Community Family Support Group
Bridge from Prison to Community Inmates Support Group
Bronco Busters SH & Exercise Program
Burlington Bereavement Resource Council
Burlington Breast Cancer Support Services

Canadian Hard of Hearing Association Canadian Heart Foundation Canadian National Institute for the Blind Candle Lighters at McMaster Caring Bears/ Diabetes Support Group Child and Adolescent Services Children and Adults with Attention Deficit Disorder /CHADD Codependency Anonymous Cognitive Behabioural Group for Depression Colectivo de Mujeres - Women's Collective Communication Skillsfor Social Anxiety Community Integration Program Community Projects Garden Group Continuing to Care - Caregivers Seniors - Support Group - Carlisle Continuing to Care Support Group - Waterdown Continuing to Care Support Group - West Mountain Council on Suicide Prevention Countdown Program Craft Group Crohn's and Colitis Foundation Cultural Interpreters Program

De Mujer a Mujer - Woman to Woman
Depressive/Manic Depressive Support for Women
Downtown Fibromyalgia Association, Hamilton Support Group

East Hamilton Sunrise Chapter # 1254/ Parents Without Partners East Indian Youth Mental Health

East Region Mental Health Services
Effective Anger Expression
Emotions Anonymous
Employment Today
Empty Arms...Empty Cradle
Epilepsy Hamilton and District
Evening Star Support Group

Faith and Light Parents Support Group
Families Against Violent Occupational Deaths and Diseases/FAVODD
Family Support Group - John Howard Society
Family United Network FUN
Fetal Alcohol Support Network
Fibro-Fit RehabilitationServices
Fibromyalgia Dundas Support Group
Fibromyalgia Support Group - East Mountain
Friends In Grief

Gamblers Anonymous
Gentle Water Exercise
Getting Our Lives Back on Track
Get On Track (smoking cessation)
Grandparents Raising Grandchildren
Grandparents Requesting Access and Dignity/ GRAND
Good Grief!
Guillan-Barre Syndrome Support Group of Canada

Hamilton Against Poverty
Hamilton AIDS Network
Hamilton Depressive and Manic-Depressive Support and Education Group
Hamilton Handicap Club
Hamilton Help Group
Hamilton Indian Women Action Group
Hamilton Parents of Multiple Births Association
Hamilton Support Group for Separated and Divorced
Hamilton Tourette Syndrome Support Group
Hamilton-Wentworth Head Injury Family Support Group
Hamilton-Wentworth Stroke Recovery Association
Healthy Eating And Life Total Harmony/ HEALTH
Heart Mates
Heart and Stroke Foundation of Canada
Hope Program

Immigrant and Refugee Women Survivors of Torture Info Plus for Women Recovering from Abuse

Kids Need Both Parents

La Leche League
Learning Disabilities Association
Living with Cancer (Dundas)
Living with Cancer (Hamilton)
Living with Liver Disease Support Group
Lupus Society of Hamilton

Men for Sobriety

Men in Grief Mothers Advocating for Youths and Adults MAYA Multiple Sclerosis Society of Canada, Hamilton Support Group

Nar-Anon Family Group
Narcotics Anonymous
New Beginnings/ Parents Without Partners #73
New Mothers Support Group
Nobody's Perfect - Parents Support Group
No Ifs. Ands. or Butts
North American Chronic Pain Association NACPA

Obsessive Compulsive Disorder Group Ontario Prade-Willi Syndrome Association Opportunities for Women Self Help Group Overeaters Anonymous

Panic Education Group
Parents Are People Too
Parents, Families and Friends of Lesbians and Gays PFLAG
Parents Helping Parents
Peer Support Program / Kidney Foundation
People's Union of Marginalized Activists PUMA
Positive Lifestyle
Postpartum Support Group
Postpolio Association of Hamilton-Wentworth
Pregnancy, Alcohol and Drugs Network
Program for Rheumatic Independent Self Management PRISM
Professional Immigrant Women Accreditation Group
Prozac Survivors Support Group

Rainbows End (Business Ventures) Recovery Incorporated Relaxation Group Roxborough Parent Support Group

Saturday Mourning Schizophrenia Information and Family Support Centre Self Esteem Course for Women Self Esteem Group (Co-ed) Self Esteem Group for Men Self Esteem / Stress Management Group for Women Self Support Group for Widows Senior's Support Group Sex and Love Addicts Anonymous Sexual Assault Centre Hamilton and Area Sibling Incest Survivors - We Have a Voice Siblings of Schizophrenics Support Group Spouses of Schizophrenics Support Group Stroke Recovery Group, Geriatric Services Stuttering Connections Suicide Bereavement Support Group Support for Sobriety - Relapse Prevention Group Support Group for Survivors of Childhood Sexual Abuse Support Group for Women Survivors [of Abuse] Support Group for Women Survivors of Childhood Sexual Abuse Teen Chronic Fatigue Syndrome Support Group
Teens Grieving in Friendship
Tenants and Homeless Information and Action Centre THIAC
Time out for You
Tinnitus Self Help Group
Tobacco Stop
Turning Point

United Disabled Consumers

Wednesday Child
Widows Self-Support Group
Widow to Widow
Women for Sobriety
Women living with Cancer
Workplace Health and Ergonomic Action Taskforce WHEAT

Young Parents' Service

Zhenmowin [AIDS Death Support]

Prepared by Ronaldo Parada, Community Development Worker

Appendix F

GROUPS IN THE CITY WE CONTACTED/LEFT MESSAGES BUT NEVER MET:

The present are self-help or support groups that we contacted through the telephone, or we left a message in their answering machine or voicemail, but never met with us. In some of the cases, they never responded to the messages, but in some other cases, they chose not to participate in the interview process. However, we sent them the same package of information created for all the self-help groups we visited, so they will be informed of the SH Centre's activities and services.

- 1- Bluebird Club
- 2- Canadian Grandparents Association
- 3- Community Sexual Abuse Program
- 4- McMaster Perinatal Association
- 5- Myalgic Encephalomyelitis Self-Help Group of Halton and Hamilton-Wentwoth
- 6- Sisterhood Of Support S.O.S.
- 7- Support Organization For Trisomy S.O.F.T.
- 8- The Alliance for Sexual Abuse:
- 9- Tough Love

Prepared by Ronaldo Parada, Community Development Worker



Appendix G

SELF-HELP GROUPS NOT ACTIVE ANY LONGER:

The following is a list of the groups that were listed in the CiS Directory, or in the List of Members of the Self-Help Network but disbanded recently or during the past few months

- 1- Fathers For Justice
- 2- Help a Child Smile Fund
- 3- Muscular Dystrophy Association of Canada Myasthenia Gravis Chapter
- 4- Ontario Network of Endometriosis
- 5- Rebounders Self-Help Group
- 6- Seniors Managing In Life Experience S.M.I.L.E.
- 7- Second Chance Heart and Lung Support Group
- 8- Sleep Disorders Canada

Prepared by Ronaldo Parada, Community Development Norker

Appendix H

GROUPS NOT ACTIVE BUT WITH A CONTACT/RESOURCE PERSON

The next groups are self-help groups that do not have regular meetings due to lack of members but one or two members still get telephone calls and provide support or/and referrals to active groups in other cities.

- 1- Caesarean Awareness and Vaginal Birth After Caesarean
- 2- Freedom From Fear Foundation

Prepared by Ronaldo Parada, Community Development Worker

APPENDIX I

Services Offered by Self Help Centres in Ontario

Profile of Self-Help Centres/Contacts in Ontario, Wednesday, August 28, 1996

CENTRE/CONTACT	A 35	* OF RESOURCES DEVOTED TO SELF-HELP	FUNDING SOURCES AND TOTAL BUDGET	SERVICES PROVIDED
4. Self-Help Centre of Hamilton -Wentworth (cont'd)	2 FTE until Jume 96 1 FTE (until September 6/96)	100 %	2 full-time staff hired by SPRC for a HRDC project to under-	a) meeting space b) referrals, although not formally
(Project of the Social Planning and Research Council)	1 FTE SPRC Planner is Building Manager but no program services	20%	take a community survey of the needs of self-help community (60 weeks at 425 per = 25,000)	offered c) answer requests for SH information
5. Self-Help Group Development Network of Sudbury- Manitoulin	1 staff @ 30 hours/week (.86 FTE) 1 staff @ 28 hours per week (.80 FTE) 1 staff @ 20 hours per week (.57 FTE)	50% to program delivery 50% to fundraising and promotion	Trillium funding 96-97 Fiscal: 65,000 97 98 fiscal: 45,000 Fundraising: 96-97 Fiscal: 10,000 directory sales 5,000 ad revenue from directory 5,000 (?) other	 b) directory c) meeting space d) assistance to start groups e) assistance to existing groups f) promotion of self-help g) resource library
6. Oxford County Self- Help Network	1.54 FTE (divided between 3 staff positions)	100%	Ministry of Health (Consumer Development Initiative) @ 88% of total budget :67,841 United Way: @12% of total budget: 11,000 Total Budget: 78.000 * there has been some fundraising but the amount raised to date has not been of great	a) resource library b) assistance to start new groups c) consultation to existing groups d) general promotion of self-help

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CENTRE/CONTACT	# OF FTE (BASED ON A 35	A OF RESOURCES DEVOTED	FINDING SCHIPCES AND	CEDVICES BOOVINGS
	HOUR WEEK)	-		
. Self-Help Network of	2 staff @ 30 hours/week	100%	100% of budget is	a) resource library
Cochrane District	(which equals 1.7 FTE)		provided by the Trillium	b) assistance to start
	as or october 1/96 FIE		Foundation:	groups
	staff 8 25 hours not		96-97 F1scal = 65,000	c) promotion of self-
	Scall & C3 flours per		7/-98 FISCAI = 45,000	help
			100a 31 anc = 110,000	d) workshops
				e) newsletter
				f) technical
				assistance to
				existing groups
				g) meeting space (?)
				i) referrals to group
Perth County CMHA	1 FTE @ 35 hours per	5-10% depending on need	100% of the position	a) resource library
	Week	and situation- self-help	relies on Nevada funds	b) assistance to start
		comes under the community	and fundralsing by the	groups
		Education Program of the	Dranch (staff position =	c) promotion of self-
			33,000)	help
				d) workshops
				e) meeting space (?)
				existing groups
				g) referral to groups
	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1			(?)
CMUA CMUA	2 FTE have self-help as	@ 10% depending on	5,000 to 10,000 (@ 10%	
	(Community Development	situation and need-	of total agency budget),	b) promotion of self-
	and Public Education)		ותותבת הא הווורבת אפא	help
				e) newsletter
				f) referral to groups

Appendix J

Focus of Group: Definition of Categories

Abuse: For survivors of sexual and/or other abuse by other people. (NOT substance abuse.)

Addiction: Groups for persons dealing with addictions, substance abuse, either by that person or someone close to the person. Includes addictions to alcohol, narcotics, tobacco, other substances, food, certain behaviours.

Bereavement: For bereaved persons in various circumstances.

Crime: Rehabilitation of ex-offenders, support by and for relatives/friends

Disability: Dealing with a longterm disability — oneself or caregiver. Includes physical disability, learning disability, sensory deficit, speech difficulties

Employment: Employment issues in various circumstances

Ethnocultural, Racial: Issues arising from specific ethnocultural or racial experiences

Men: For men only, various topics

Mental Health: Mental health -- promotion, recovery, management, prevention of illness, certain syndromes....

Parenting: Support for people doing parenting in various circumstances

- Children with certain illnesses, syndromes, health or developmental problems
- Expectant & newborn parenting up to preschool age
- For single parents only OR includes specific help for single parents
- Various specialized circumstances: parenting in a foreign culture; parenting teenagers; parenting twins and more; parenting teenagers; parents of homosexual children; parenting grandchildren.

Physical: Physical issues -- health promotion, disease or physical syndrome management

Seniors: Issues of aging; caregivers of seniors; grandparents

Separation & Divorce: On issues generated by separation & divorce — Includes dealing with pain, loss, grieving post-separation; also custody & access issues, single parent groups.

Sexuality: Issues related to sexuality (but not Sexually Transmitted Disease - see under Physical)

Social advocacy: Action directed toward public awareness and legislative change

Suicide: Suicide - bereavement, prevention, attempt survivors

Violence & Torture: Groups dealing with issues of violence, assault, torture

Women: For women only, various topics

Workplace Safety: Workplace issues - occupational health & safety

Youth: For youth - children, teens, young adults, young parents; some include parents of youth

Appendix K

Self Help Centre Membership-- One example of how it might be Restructured

In order to: 1) make it more affordable

2) align costs, benefits, needs and mandate

3) make it more widely beneficial and attractive

- Eliminate current categories of Full, Associate-Group and Associate-Individual membership.
- Create one Membership, available to all interested groups and individuals, at a cost of (say) \$20.00 per year. (This could, of course, be adjusted based on further discussion.)
- Benefits to all members to include:

Newsletter (make it available!)

Newsgroup (using, for example, the computers in the Nerve Centre)

1 vote at the Annual General Meeting

10 % discount on events and publications

Create separate Benefits Packages as follows:

Mutual Aid Benefits (available only to self-help/mutual aid groups): Meeting room available for group meetings on a cooperative basis throughout the membership year at the rate of \$5 per 4 meetings (2 hours or 1 evening each, as often as once a week) up to a maximum of \$50 per year. That amount could be paid in full when membership is renewed, or in multiples of \$5 that are more manageable for the group. Total membership plus MA Benefits comes to \$70.00 per year, a slight decrease from current Full membership cost. Meeting rooms after the fortieth meeting are, of course, available under the same terms at no further cost that year.

Rooms for fundraising events available for rent at 10% off full rate.

General Benefits (available to all other members)

Meeting rooms available for rent, subject to self-help priorities, at 10% off full rate.

While this would bring in less per self-help group, especially if some bought less than \$50 worth of benefits, membership would in general be much more widely attractive. Iincreased membership could quickly offset the losses -- possibly even earn more revenue than before.

HAMILTON PUBLIC LIBRARY

